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Rare Diseases Website
Developing the Parent-to-Parent Content
of a
Rare Disease Website in Ireland
(RD-WEB P2PS)

An exploratory study to further explicate parents' requirements to effectively provide parent-to-parent support on an Irish website for parents of children with rare conditions.

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Executive Summary

Introduction

The primary purpose of this follow-up descriptive exploratory study was to further investigate the development of an Irish website for parents of children with rare conditions specifically with regard to the development of a live parent-to-parent support platform feature on that website. The previous study, *Rare Diseases Web-Information for Families in Ireland* study *(RD-WIFI)* (Nicholl *et al.* 2014) served for the first time in Ireland to explore with parents the development of an innovative and culturally appropriate Irish website for parents of children with rare conditions. The study identified parents need for a dedicated Irish website that was easily accessible, live, up-to-date, disability friendly, interactive and linked to national and international organisations. In relation to content, findings reported that content be presented in plain understandable language in English and Irish, be reliable and credible, balanced in its presentations, 'not just the science but also real life stories' and provide up-to-date research information.

One of the most compelling findings from the RD-WIFI study (Nicholl *et al.* 2014) was the identified need for a live parent-to-parent support platform feature and that this feature should be included in the design of the proposed website. Building on this, the current study set out to further investigate, with parents, the concept of a live parent-to-parent support platform feature. The strategy of involving proposed users in the exploration is strongly supported by Paterson *et al.* (2013), who found that in the development of most online social support interventions the target population was excluded, resulting in interventions that did not reflect the needs of that population.

This study is timely in that the National Rare Diseases Office, a development of the National Rare Disease Plan (2014), was launched in July 2015 (Varadkar 2015).

The School of Nursing and Midwifery at Trinity College Dublin, in collaboration with the Saoirse Foundation was awarded funding from the Irish Research Council "New Foundations" Scheme, to conduct this follow-up study. The aim was to further examine the requirements of parents for a live parent-to-parent support platform.

The key objectives of the study were to:

- build on the previous study's findings which recommended a live parent-to-parent support platform;
- determine where parents' currently acquire online parent-to-parent support;
- determine the nature of the parent-to-parent support that is being sought by parents online;
- identify any gaps in terms of current online parent-to-parent support; and
- determine the most important features, support and information a live online parent-to-parent platform should include/provide.

Methodology

A descriptive exploratory methodology was employed. The sample consisted of parents of children with rare conditions. A purposive non-probability sample of ten parents was recruited via the Saoirse Foundation (SF) who acted as gatekeeper. A total of eight interviews were conducted, one focus group with three participants and seven individual telephone interviews. Ethical approval was obtained from the School of Nursing and Midwifery Ethics Committee, Trinity College Dublin.

Data collection consisted of a systematic literature search, a literature review and qualitative interviews. Biographical data were analysed using simple descriptive statistics in MS Excel. All participant views were combined for simple thematic data

analysis (Aronson 1994, Nicholl *et al.* 2014). To protect identities, all participant interviews were coded.

Findings

All participants were mothers and the majority were employed, had a higher level of education and lived in urban settings. All children reported on in this study had a diagnosed condition, two were diagnosed at birth, others were diagnosed as toddlers and young children while two were diagnosed when teenagers.

Parent-to-Parent Support for Parents of Children with Rare Conditions

- All participants had accessed parent-to-parent support. All but one found this support was and continued to be most important in developing their understanding of their child's condition and in assisting them in caring for their child. Parents also sought support in order to reduce their sense of isolation, feel less alone and to find other parents who shared similar situations.

Online Parent-to-Parent Support

- All participants had experience of accessing online parent-to-parent support communities. Generally, due to the rareness and in some cases the extreme rareness of their child's condition, online parent-to-parent support was difficult to access in Ireland. To find support, participants accessed sites from other English speaking countries, for example, Australia, Canada, New Zealand and also the United States of America. International online resources were used for a variety of reasons including, seeking information about their child's condition, asking questions, making contact with other parents to talk about their children with whom they felt would understand. While participants found these international supports helpful, they also viewed them as limited.

Why an Irish Social Networking Parent-to-Parent Support Site

- All participants viewed an Irish live social networking site (SNS) as essential for providing parent-to-parent support. They felt that they, as parents living in Ireland, need the support of a community sharing experiences similar to their own. They viewed that this SNS would enable them to share similarities around issues such as diagnosis, treatment and the health and education systems. They held that while this SNS would have links to international organisations, information and other related issues, it essentially, would be Irish, supporting parents in Ireland and providing Irish information.

- A key finding was the view that Facebook support, while very important, was not sufficient as participants' indicated that they also required face-to-face meetings. In almost all interviews, face-to-face meeting events were viewed as essential to their support needs. For participants, meetings and events publicised on non-Irish live network sites had little relevance for them. They thought that an Irish SNS could serve to promote face-to-face meetings in Ireland, including at least one annual family day.

The Proposed Website and a SNS

Findings support those from the RD-WIFI study (Nicholl *et al.* 2014) regarding the call for an Irish website for parents of children with rare conditions.

- This study expands on findings from Nicholl *et al.* (2014) to include the provision of a live parent-to-parent SNS feature on the website. It was also suggested that the proposed website be linked to official sites and most importantly, a link to the recently launched National Rare Diseases Office should also be provided. In

addition, both the website and SNS should be administered and monitored in line with current best practice.

- With regard to the SNS, it was suggested there could be a private Facebook page with restricted access for registered members and a public page for general access. Participants stated that the Facebook pages would need to have an administrator/moderator with the private page perhaps being password protected. Members would need to login to gain access. In setting up the SNS care would be needed when developing features for creating profiles and ensuring restricted access to members. It was suggested that providing details about the child's diagnosis and age could be used for members' login. For the majority of participants, group forums on websites were considered to be an advantage, places where people are able to share similar experiences. Some parents suggested that a Dad's and a sibling's forum would also be useful.

Website Content

- This study expands on findings from Nicholl *et al.* (2014) with regard to website content. Parents would like to see that it is possible for their child to transition from childhood to adulthood, therefore, they would like to see descriptions of conditions across the lifespan of the child rather than the sole focus on the young child. Also, they would like information on undiagnosed conditions and those that are unexplained. Similarly, they would like to be provided with information on clinical trials that are being conducted. Some participants spoke of developing a database containing parent details similar to Unique. They also suggested that the proposed website should have a system in place for parents to be able to contact 'expert groups' of parents.

- Participants would like webpages specific to the Irish context and others that provide international information. According to them, the pages with information specific to the Irish context should include material on all relevant Irish services,

for example, health, social protection and education services as well as events in Ireland. The international pages should provide information and news on rare conditions and research into those conditions. Participants would also like the site to have links to relevant organisations as well as specific sites that they particularly favoured in terms of what they offered.

Information and Communication Technology

- In designing a future Irish parent-to-parent support SNS for parents of children with rare conditions it will be essential to have knowledge of the information and communication technology (ICT) skills and preferences of the proposed user. In accessing SNSs all participants used smartphones and to a lesser extent, computers including laptops.

- Facebook was participants' first choice when accessing SNSs. Websites were accessed purely to gather information. In general, specific conditions' websites were accessed, as participants viewed 'official' websites to be useful for obtaining diagnostic and medical information. In seeking support, participants chose Facebook over websites because they felt that websites do not capture the individual needs of the child, the variability and complexity of their condition. For parents, Facebook provided access to other Facebook users who they viewed were usually living through the same experiences.

Recommendations

This study recommends the provision of an Irish website for parents of children with rare conditions as proposed by Nicholl *et al.* (2014). In addition, this website should contain a live parent-to-parent social networking site (SNS) feature.

- ➢ Design of the website needs to consider the following:

- o All information to be provided by trusted sources.

- o The site should be smartphone/computer/tablet-friendly.

- o Provision of a live parent-to-parent SNS feature which would:
    - be administered and monitored in line with best practice
    - include an events element promoting parent and family meetings including an annual family day.

- ➢ Links on the website to include:
    - Irish official websites for health, education, welfare and social services
    - The National Rare Disease Office
    - Irish rare condition specific organisations
    - Irish organisations for parents, families and children with special needs
    - official international websites for rare conditions and other health related websites
    - international rare conditions specific organisations.

- ➢ Development of the website should:
    - have continued involvement of parents of children with rare conditions
    - take cognisance of potential users' level of ICT skills and preferences
    - benchmark the design, layout and content against other appropriate first rate Irish and international websites.

- ➢ Future research into the:

- o level of ICT skills and preferences of potential users
- o role of healthcare professionals in the development and provision of a live parent-to-parent SNS feature
- o inclusion of 'expert' parents in the development and provision of a live parent-to-parent SNS feature
- o inclusion of a support feature for siblings.

Table of Contents

List of Tables and Figures

Glossary of Terms

For the purpose of this report terms used are defined as:

Child: Person below the age of 18 years.

***Family:** A family is defined as those closest to the patient in knowledge, care and affection who are connected through their common biological, legal, cultural, and emotional history.

Healthcare Professional: A healthcare professional is defined as a children's outreach nurse, general practitioner, healthcare assistant, paediatric consultant, physiotherapist, public health nurse, social worker, speech and language therapist and or a healthcare professional involved in the care of children with rare conditions and or those requiring palliative care.

ICTs: Information and communications technologies refers to the technological devices individuals use, such as desktops, tablets, smart phones etc. as well as software and applications used on these devices (Rudi *et al.* 2015).

Internet: the large system of connected computers around the world that allows people to share information and communicate with each other (Cambridge Dictionaries Online).

***Life-limiting conditions:** Life-limiting condition means a condition, illness or disease which: a) is progressive and fatal; and b) the progress of which cannot be reversed by treatment (The Scottish Parliament 2010).

****Life-threatening conditions**: Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included.

Online: Refers to using the internet (Cambridge Dictionaries Online).

Parent: Refers to and includes mothers, fathers, legal guardians and/or caregivers.

Parent-to-parent support: Parent-to parent support "exists in any situation in which parents are able to share information and provide emotional support" (Law *et al.* 2003).

Platform: A system that can be programmed and therefore customized by outside developers, that is users. It can be adapted to countless needs and niches that the platform's original developers could not have possibly contemplated, for example, Facebook. Source: http://www.programmableweb.com/news/what-platform/2007/09/19 [accessed 13th September 2015]

Rare conditions: findings from a previous study, *Rare Diseases Web-Information for Families in Ireland* study *(RD-WIFI)* (Nicholl *et al.* 2014) indicated that all parents preference is for the term "rare condition" when referring to their children's rare condition, disorder or disease. In acknowledging this preference, rare condition, in this report refers to and includes rare conditions, rare diseases and rare disorders.

SNS: Social networking site is a web-based application such as Facebook that allow individuals to present themselves, establish or maintain connections (Ellison *et al.* 2007).

Website: This refers to pages of information on the internet about a particular subject. These can be published by a single person or organisation. Websites are often static, non-interactive, just providing information. (Based on a definition from Cambridge Dictionaries Online).

Sources: * Health Service Executive (HSE) (2014) Glossary of Terms. Health Service Executive National Clinical Programme for Palliative Care, Clinical Strategy and Programme Division. **Department of Health and Children (2009) Palliative care for children with life-limited conditions in Ireland: A National Policy. Department of Health and Children. Dublin.

Chapter 1: Background and Introduction

A previous study, *Rare Diseases Web-Information for Families in Ireland* study *(RD-WIFI)* (Nicholl *et al.* 2014) explored the development of an innovative and culturally appropriate Irish website for parents of children with rare conditions. This study identified parents need for a dedicated Irish website. It reported that parents would like the site to be easily accessible, credible, balanced in its presentations, live, up-to-date, disability friendly, interactive and be presented in plain understandable language in English and Irish. Parents would also like the site to have links to national and international organisations and provide details of support groups and support organisations. Parents wished the site to provide reliable and credible information, not 'just the science but also real life stories' (Nicholl et al. 2014:29) as well as up-to-date research information. It was also reported that there should be multidisciplinary team involvement, with healthcare professionals, including those with specialist expert knowledge, facilitating interactivity with parents. In addition, it was proposed that there should be some form of psychological contact support for parents.

One of the RD-WIFI study's most compelling findings was parents' identification of their need for a live parent-to-parent support feature on the website. It was recommended that this feature be included when designing the proposed website. Building on this finding, this study specifically further investigates the provision of a live parent-to-parent support feature on the proposed website.

In Chapter Two the methodology is set out, while Chapter Three provides a literature review setting the context within which the report can be fully understood. Chapter Four presents the key findings and Chapter Five sets out a discussion and the study's recommendations.

Chapter 2: Methodology

2.1 Introduction

This chapter outlines the methodology employed in this descriptive exploratory study. A qualitative design was used to capture parents' views on the provision of a live parent-to-parent support feature on a designated website. It outlines the aims and objectives, the recruitment of the sample, inclusion and exclusion criteria, ethical approval, and methods of data collection and analysis.

2.2 Aims and Objectives

The aim of this follow-up study is to further examine parents' requirement for a live parent-to-parent support platform, which parents in the previous RD-WIFI study (Nicholl *et al.* 2014) reported they would like. The proposed website for parents of children with rare conditions would be the first Irish website providing such a service.

Objectives to:

- build on the previous study's findings which recommended a live parent-to-parent support platform;
- determine where parents' currently acquire online parent-to-parent support;
- determine the nature of the parent-to-parent support that is being sought by parents online;
- identify any gaps in terms of current online parent-to-parent support; and
- determine the most important features, support and information a live online parent-to-parent platform should include/provide.

2.3   Recruitment of the Sample

The sample for this study consisted of parents of children with rare conditions. A purposive non-probability sample of ten parents was recruited via the Saoirse Foundation (SF) who acted as the gatekeeper for this study. The SF advertised the study via its website, social media links, conferences and staff also assisted in recruitment. For recruitment to the focus group SF provided potential participants with information on the study which included a letter of invitation (Appendix 1) and information sheet (Appendix 2). For telephone interviews potential participants were also provided with an information sheet (Appendix 3) and a letter of invitation (Appendix 4). Following expressions of interest to take part in telephone interviews, potential participants were emailed a consent form (Appendix 5), a demographic questionnaire (Appendix 6) and information about the interview questions.

2.4   Inclusion and Exclusion Criteria

Included in the study were parents of a child with a rare condition who expressed an interest in attending the focus group or taking part in a telephone interview. Excluded from the study were those parents who, having received the study's information declined to participate.

2.5   Ethical Approval

Ethical approval was obtained from the School of Nursing and Midwifery Ethics Committee, Trinity College Dublin. The study adhered to the principles of good ethical practice in research as identified by the International Council of Nurses (2006). Participants volunteered to participate in this study and were free to withdraw at any time without penalty. With participants' permission all interviews were audio recorded, confidentiality was assured and participants were assured that any identifiers from the interviews would not appear in any report, publication or presentation so all quoted data

are coded. All study data were stored in a secure location and access to raw data was restricted to the research team.

Prior to participation in the study, focus group participants gave written consent. They also completed a demographic questionnaire and during the interviews pseudonyms were used to protect participants' identities. Prior to each telephone interview participants were emailed a consent form and a demographic questionnaire. Before the interview commenced participants' consent was obtained and audio recorded, the interview began with the audio completion of the demographic questionnaire. One participant prior to the interview chose to complete and return the consent form and biographical details, this consent was confirmed by telephone and audio recorded.

2.6   Data Collection

Data collection consisted of a systematic literature search (Appendix 7), a literature review (Chapter 3) and qualitative interviews. A purposive sample of parents of children with rare conditions, (n=10) was recruited. A total of eight interviews were conducted, one focus group (n=3 participants) and seven telephone interviews with individual participants.

Initially the study sought to hold nationwide focus groups across four centres. One focus group was held and following difficulties in obtaining sufficient numbers to conduct further focus groups, the researchers collected data via telephone interviews. Telephone interviews were chosen as the most appropriate option as literature indicates (Miller 1991, Carr and Worth 2001, Drabble *et al.* 2015) that while people tend to give shorter responses over the telephone, they discuss as much and express the same views when compared with other interview methods (Ainbinder *et al.* 1998). To ensure consistency across interviewing one interviewer conducted all interviews (Ainbinder *et al.* 1998).

In both the focus group and the telephone interviews semi-structured interview guides were employed (Appendices 8 and 9). Following the focus group, the telephone interview guide was modified to reflect issues that arose. Both guides had key questions which provided guidance during the interviews while also allowing for discovery and elaboration (Gill *et al.* 2008). At the end of the focus group, the second researcher provided participants with an overview of the contents of the discussion which allowed participants the opportunity to give feedback and confirm group conclusions (Webb & Kevern 2001, Massey 2011). Prior to ending the telephone interview, the interviewer asked participants if they had any additional comments or if there was anything that had not been covered.

2.7   Analysis

Biographical data were analysed using simple descriptive statistics in MS Excel. The interview guides were used as the analytical foundation for all other data and all participant views were combined for simple thematic data analysis (Aronson 1994, Nicholl *et al.* 2014). To protect identities, all participant interviews were coded. Sets of quotations from all interviews were chosen to represent the themes presented. In presenting findings, distinction is made between those parents who took part in the focus group and those who took part in the telephone interviews. Focus group quotations are presented as (FG) and telephone interviews as (TI) (McGarvey & Hart 2008).

Chapter Three: Literature Review

3.1 Introduction

The role of information technology, and in particular the Internet, has increased in past decades and is increasingly becoming an important part of our day to day lives (Gallagher *et al.* 2008). People increasingly spend time on the Internet searching for an explanation, diagnosis or treatment for their symptoms. The expansion of the Internet has resulted in widespread availability of medical information for both patients and physicians. The Internet can empower users to seek help and increase understanding of their medical conditions (McMullan 2006). Eurostat (Seybert 2011) have recently reported that more than half of individuals (56%) in the EU use the Internet every day, whilst 68% go online at least once a week (Glynn 2013). A key driver in the growth of the Internet has been the introduction of Internet-enabled 'smartphones', and these devices are now emerging as everyday platforms for accessing information and managing daily routines; there are currently an estimated 1.08 billion smartphones globally, with 84% of users using their devices to browse online, and 69% downloading applications (Glynn 2013). Prior to the information technology era information and advice was sought and obtained from health professionals, pharmacists, extended family, neighbours, text books and journals. Access to such information was both slow and difficult in some cases. Since the advent of the Internet, and its growth in various forms of social media, there is a wealth of information available at the touch of a button. This information is available at any time of the day for usage all over the world. Apart from the Internet's provision of information and the ability to purchase, there has also been a growth in its usage for the provision of support. Currently the Internet is a major provider of health related information, with 72% of users in the US and 71% Europe 71% seeking such health related information (Nölke *et al.* 2015).

3.2   Support for Parents of Children with Rare Conditions

Before Internet usage became commonplace, people diagnosed with a rare condition and parents of children with a rare condition had difficulty in obtaining information about specific rare conditions and in connecting with others with the same rare condition (Beall 2001). The use of the Internet for searching and sharing health information and for health care interactions may have great potential for families of children affected with rare conditions (Tozzi *et al*. 2013).   Indeed, the use of the Internet for health care interactions may represent a necessity in enabling patients with rare conditions to better manage their complex health needs (Tozzi *et al*. 2013). Parents of children and young people with rare conditions have varying needs for both information and support during the course of their child's life. Searches range from seeking a diagnosis, confirming a diagnosis, seeking expert advice and centres of care and establishing their entitlements in relation to State and voluntary services (Nicholl *et al.* 2014). The very nature of caring for children with life-limiting conditions places a heavy workload on the parents and as a consequence parents may turn to Internet usage for both information and support. Parents also need to be able to access such services on mobile devices while they are in hospitals or other medical settings (Nicholl *et al.* 2014). The Internet offers many opportunities to provide parenting support to parents (Nieuwboer *et al.* 2013). In their systematic review, Nieuwboer *et al.* (2013) outlined that the Internet offers a variety of opportunities for sharing peer support and consulting professionals. They identified a wide range of supports available to and used by parents. Some of these include chat rooms (open and confidential), discussion boards, websites monitored / controlled, or not, by health professionals or peers, wiki and many other sources. The types of support range from child health information to parenting skills and parent craft. Nieuwboer *et al.* (2013) suggest that the first generation of online resources has already changed parenting and parenting support for a large group of parents and professionals. However, using an Internet search engine to find out information risks linking to sites that have no medical authority or who are pursuing a commercial agenda.

3.3   Types of Support Searched for by Parents

Information and support for parents, and indeed their children, may be difficult to access online. Some parents do not have a diagnosis of their child's symptoms and this raises many issues in relation to their searches. The accounts of other parents' experiences may be unhelpful as sometimes the *worst case scenarios* are presented as being *typical.* Parents are usually seeking information and support in relation to the real time issues they are encountering and may not find appropriate sources of help. Dworkin *et al.* (2013) in their literature review of parents' online behaviour reported that parents are looking for parenting information and social support online. Importantly Dworkin *et al.* (2013) also noted that the trustworthiness and credibility of information is very important to parents. A strategy parents use to assess the trustworthiness of websites was to identify and evaluate the source of the information presented on the website (Bernhardt & Felter 2004). Mothers were most trusting of information written by physicians and nurses (Bernhardt & Felter 2004). Parents in the Bernhardt & Felter (2004) study reported that perceived trust of specific web sources could increase over time as they became more familiar with the source. Information repetition and convergence was also important to mothers, information appearing several times in many different places was considered to be more trustworthy than information that was not repeated (Bernhardt & Felter 2004). The importance of a website being reliable and evidence based in its information cannot be overstated for parents.

Paterson *et al.* (2013) noted in their study about parents engagement in online support that there was a "digital divide" between parents who were described as socioeconomically advantaged compared to parents who were socioeconomically disadvantaged. They also identified the highest level of users were urban Caucasian women who are well resourced in terms of education and income and less than 35 years of age (Paterson *et al.* 2013). This raises issues of accessibility to technology and social support sites, education and lack of resources for many parents. There is some suggestion in the research that the digital divide may be shrinking, however, among a

low income, low education sample of parents, those with the lowest income were least likely to have access to a computer at home (Kind *et al.* 2005).

Many studies have reported the needs of parents seeking information and support on the Internet. The act of searching for and accumulating information via the Internet can be important for coping emotionally with a situation characterised by uncertain prospects and inadequate information from health personnel (Gundersen 2011). Parents want current, valid and reliable information and they need the information to be relevant to their personal situation and to be offered on a site that is easy to navigate. Gundersen (2011) interviewed ten Norwegian parents whose children had different rare genetic conditions. The parents reported that they used the Internet as a resource and that seeking information and becoming knowledgeable were tremendously important for parents upon learning that their child has a rare genetic condition. Similar to other studies, a main reason for these parents' intensive information seeking, facilitated by the Internet, was their experience with the health system. The medical personnel they dealt with were unable to provide them with sufficient information and so parents had to become the 'experts' capable of advocating their child's interest (Gundersen 2011).

Gundersen (2011) noted in his study that the process of adjusting to, and coping with, life when parenting a child suffering from a rare genetic condition involves becoming knowledgeable about the child's condition and this knowledge is essential for gradually comprehending and managing a situation that initially seems unmanageable and distressful. The type of knowledge parents search and find on the Internet include genetic databases, scientific research on the human genome and genetic conditions, diagnostic tools, online social networks formed around specific genetic conditions and other resources related to medical information. Gundersen (2011) also suggests that as parents adjust so does the frequency and purpose of their Internet searches.

Parents engage in online social support and searching to meet their information need and the need to communicate with other parents who share a similar reality (Paterson *et al.* 2013). Pimentel *et al.* (2013) in their study involving parents of children with Cystic

Fibrosis (CF) noted that the Internet proved to be a medium of opinion formation which could eventually replace medical advice. It is therefore necessary to establish criteria for constructing and monitoring information related to CF published on Internet websites (Pimentel *et al.* 2013). However, parents have reported that the Internet support services can be somewhat impersonal and that they missed the face-to-face contact aspects of communication where facial expression, tone and non-verbal elements were not present. Absence of these elements of human interaction could lead to misconceptions in the interpretation of information being imparted. The suggestion of the addition of a phone call or the use of Skype could be considered by parents (Binford-Hopf *et al.* 2013).

Interestingly, Glynn (2013) in their study reported that despite the widespread use of the Internet, respondents in their study still ranked it less important relative to traditional sources of health information. Similarly, Khoo *et al.* (2008) reported that the clinician remains the most important source of information for parents. An opportunity exists for clinicians to become the gateway to the Internet for parents by identifying sites that are accurate and trustworthy (Khoo *et al.* 2008). Importantly Khoo *et al.* (2008) also notes that healthcare professionals can identify those websites which are potentially damaging to the patient or parent, and subsequently advise them to avoid visiting those sites.

The US site www.rareconditions.org from the National Organisation for Rare Conditions (NORD) is aimed at parents of children diagnosed with rare conditions and health professionals, and has a database of summary reports about more than 1000 rare conditions (Odegard 2007). The database is structured by the name of the condition, with summary reports containing a list of synonyms for the condition, a brief summary of the characteristic features, and a directory of related organisations with their contact details and web address (Odegard 2007). The advantage of the NORD site is that the information is very authoritative, with content written by medical writers and reviewed by

physicians (Odegard 2007). NORD is a US non-profit, voluntary health agency that exists to serve rare condition patients and their families.

Similarly, EURORDIS is the European equivalent and is also a non-governmental patient-driven alliance of patient organisations representing 678 rare condition patient organisations in 63 countries. EURORDIS is the voice of 30 million people affected by rare conditions throughout Europe. RareConnect is an initiative which aims to engage patients with rare conditions in these communities and was created by EURORDIS and NORD. It is a platform where individuals and families affected by rare conditions can connect with each other and find helpful resources. The International Rare Conditions Research Consortium (IRDiRC) was initiated by the European Commission and the US National Institutes for Health Research (NIHR) and launched in April 2011 to foster international collaboration in the rare conditions field. The IRDiRC aims to team up researchers and organisations investing in research on rare conditions in order to achieve two main objectives, namely to deliver 200 new therapies for rare conditions and to diagnose most rare conditions by the year 2020.

3.4   Online Parent-to-Parent Support

The advent of the Internet has had a tremendous positive impact on the dissemination of information about rare conditions. Indeed the use of the Internet may be an important tool in the diagnostic process and in finding support for those invited (Bouwman *et al.* 2010, Beall 2001). The expansion of the Internet has resulted in the widespread availability of medical information for both patients and physicians (Bouwman et al. 2010). One of the positive aspects of parent-to-parent support using the Internet is that large groups of people, both within Ireland and internationally, can be readily contacted and it facilitates both sharing of information and provision of support. The global aspect is of particular importance for parents who have a child with an extremely rare condition who cannot locate a similar family in Ireland.

Bouwman (2010 p.643) outlines the 'lengthy diagnostic odyssey' that some parents with children with rare conditions encounter searching for a diagnosis. The use of the Internet may indeed assist in overcoming some of the issues such as geographical distance and isolation issues (Niela-Vilén *et al.* 2014). The global aspect to Internet usage may also speed up the dissemination of new research findings in relation to a wide variety of rare conditions and conditions. Parents can now find a huge amount of information and support on the Internet that is accessible, anonymous, cost effective, and convenient (Nieuwboer *et al.* 2013).

Online communication also provides the critical mass of people needed for support for parents and facilitates finding information about rare conditions. Glenn (2015 p.18) describes findings from her study which demonstrate 'connectedness' which is vital for parents who feel isolated and enabled them to form groups with parents in similar situations. Parents have discussed 'online triggers' which could bring about feelings of sorrow and transmission of misinformation and information overload (Glenn 2015 p18). According to Glenn (2015) parents can feel a sense of empowerment by receiving information and support which helps in regaining a sense of control. The parents in the Glenn (2015:21) study also reported 'seasons of online communication' which reflected their experiences at the various times they were using online support or seeking information in the trajectory of their child's illness. Their use of online communication seemed to change over time as they gained confidence and their child grew older (Glenn 2015).

In a systematic review carried out by Niela-Vilén *et al.* (2014 p.1532) the authors noted that the *"Interne-based peer support provided emotional support, information and a social community for mothers"* and that both mothers and fathers enjoyed the experience of being in contact and sharing their experiences with other parents. The ability to express their feelings and vent was valued by parents as such venting may not always be socially acceptable in all situations (Hans & Belcher 2001). Parents have reported that the information received from other parents met their needs better than information provided by professionals. They felt other parents could relate in a more

meaningful way to their unique experiences (Niela-Vilén *et al.* 2014, Binford-Hopf *et al.* 2013).

Social networking is one of the most popular activities on the Internet (Jung *et al.* 2014). Jung *et al.* (2014) also note that studies acknowledge that social support seldom directly influences negative effects, but importantly can buffer negative influences of stressful situations on one's psychological health. Social support using the Internet can provide emotional support, such as expressions of concern and compassion; informational support, such as advice or information to help make decisions; instrumental support such as providing practical assistance and resources and affirmative support, such as providing positive feedback about the persons behaviour and decisions (Lin & Bhattacherjee 2009 cited by Paterson *et al.* 2013 p.114). The sense of empowerment of parents following social support was identified by Paterson *et al.* (2013) and this was felt to help them cope with their child's condition. However the non-involvement of parents in online support seeking was also noted and requires further research.

3.5   The Provision of Online Support for Parents of Children with Rare Conditions in Ireland.

The development of the Internet and subsequent evolution of social networking has significantly changed the effectiveness of patient advocacy groups for rare conditions (Black & Barker 2011).The greatest degree of change has occurred at the patient level, with an increased ability of affected individuals to share experiences and support, and to raise public awareness (Black & Barker 2011). The creation of an online site which will be accessible valid, reliable, easy to navigate and disability friendly would be welcomed by parents (Nicholl *et al.* 2014). The requirements for such a site, identified from the literature and by parents, should involve the following elements. The site needs to have visible links to related sites of interest, including current research findings, information on ranges of therapies available, location of experts in the related fields and the full range of state services and entitlements available. Links to special sites such as specific

rare conditions /conditions websites, support groups and discussion rooms, with and without a moderator service, are an important element of support websites. The facility to use pseudonyms has been identified by Niela-Vilén *et al.* (2014) and (Binford-Hopf *et al.* 2013) in order to protect a parent's identity and facilitate freedom of expression. Parents have expressed concern in relation to hacking and Internet security and have requested that websites should have a server which is Firewall-protected and password protected (Binford-Hopf *et al.* 2013). Parents, as users of support group interventions, should be involved in the creation and design of such sites and their engagement with such planning requires recognition in relation to the engagement of other parents in the future (Paterson *et al.* 2013).

3.6   Conclusion

The use of the Internet as a source of health information has increased over the years. The Internet has democratised access to health and diagnostic information, enabling patients to mobilise social support from peers, these possibilities are particularly important for patients and caregivers confronting a rare medical condition (Gundersen 2011). Information provided by the health care system through traditional channels may not sufficiently fulfil the knowledge needs of parents of children with rare conditions (Tozzi *et al.* 2013). Parents and carers of children with rare conditions are often isolated from others in similar situations. The Internet therefore provides a unique mechanism through which they can make contact and share experiences and information about the condition. Perhaps the greatest value of the Internet, from a health care consumer's perspective in relation to rare conditions, has been the creation of online support groups (Beall 2001), as parent-to-parent support groups are an important means for communication and sharing information among parents of children with rare conditions.

The Internet has facilitated communication among researchers and scientists conducting research on rare conditions and has increased the flow of information between them and patients (Beall 2001). Collaboration between support groups and

researchers, facilitated by modern media, can lead to better healthcare and quality of life for all with rare conditions (Baas *et al.* 2014).

Chapter Four: The Findings

4.1 Introduction

The aim of this follow-up study is to further examine parents' requirement for a live parent-to-parent support platform, which parents in the previous RD-WIFI study (Nicholl *et al.* 2014) reported they would like. This chapter presents the findings from the focus group discussion and the telephone interviews. Findings are presented under the following headings: biographical data; why seek parent-to-parent support; current sources of online parent-to-parent support; why an Irish live parent-to-parent support platform; an Irish website proposal; and proposal for an Irish live parent-to-parent support platform.

4.2 Biographical Data

Biographical data are presented for the participants (n=10) who took part in the study and for the children (n=10) reported on in the study.

4.2.1 Participants Profile

All participants were mothers (Powell *et al.* 2011, Hand *et al.* 2013, Oprescu *et al.* 2013, Nicholl *et al.* 2014). Four were in the age range 35-49 years, three in the range 18-34 years and equally three were aged 50 to 64 years (Figure 3.1). The majority of participants (n=4) had completed undergraduate education, three postgraduate education, two vocational training and one secondary school (Dworkin *et al.* 2013, Hand *et al.* 2013, Glynn *et al.* 2013, Paterson *et al.* 2013, Nicholl *et al.* 2014). The majority (n=5) lived in a city, three in a town, one in a village and one in a rural location.
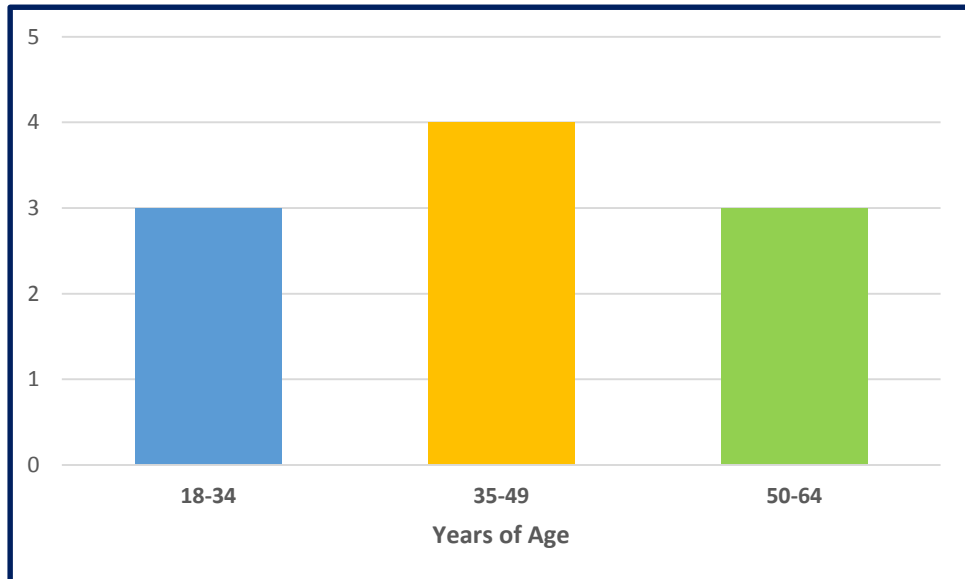
Figure 3.1: Age Range of Participants

Four participants stated that their primary occupational role was "their child's main carer", three reported that they were "employed full-time" and two were "employed part-time". One participant described their primary role as "homemaker and their child's main carer".

4.2.2 Profile of Children Reported on in the Study

Six of the children were male and four were female. Their ages ranged from two years to thirty-one years. Six were aged ten years or younger and four were aged 11 years and over.

All children had a diagnosed condition. The majority (n=4) were diagnosed when infants, including two children diagnosed at birth. Two children were diagnosed when toddlers and two were aged between four and 11 years at diagnosis, while two received a diagnosis when teenagers (Figure 3.2). The diagnosed conditions were across a

range of rare conditions. The rarity of the conditions reported on, means that some of the conditions were, as far as parents were aware, possibly the single or one of a single digit number of such conditions diagnosed in the country. Due to this and in order to protect the identities and confidentiality of the children and their parents the conditions will not be reported in this report.
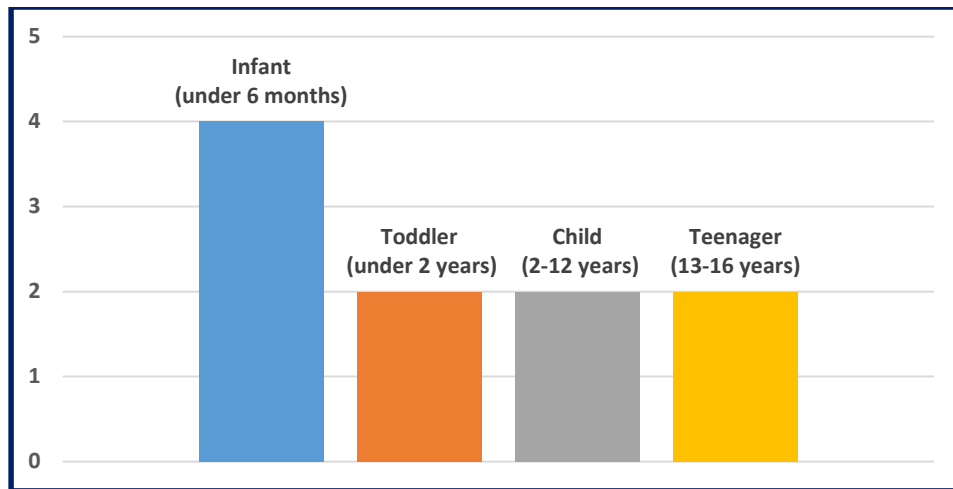
Figure 3.2: Children by Age at Diagnosis

4.3   Why Seek Parent-to-Parent Support

All participants had experience of parent-to-parent support. All but one found this support was, and continued to be, most important in developing their understanding of their child's condition and assisting them in caring for their child. For these participants, the rareness, and in some cases, the extreme rareness of their child's condition meant that finding other parents in similar situations was a *"great support"* (TI10) and for some it was or is important because:

> *Only support parents have, doctors do not know about it…*(TI09) and *Parents from their experience give information and advice to other parents…*(TI05)

When asked about why they sought parent-to-parent support, participants said it was:

Out of necessity that is what parents have to do…other parents tell you about these things, parents are brilliant, really are… (FG01)

For support really to find other parents in the same situation… (TI05)

For participants, engaging in parent-to-parent support helps in many ways, such as, learning from others, being able to offer advice to others and giving vent to feelings. Guidance is also provided, with one experienced parent reporting that she advised another parent, who was starting out her "journey", to remember:

What is a problem to-day won't be a problem tomorrow but you will have a new problem… (TI07)

Gives you insight into what might happen down the line…I will know what is to expect…also, I can give advice… (TI05)

Learning from others:

Learning that deletion and duplication children are alike although may have different conditions… (TI09)

Having someone to talk to:

To give out – that is what people use it for – husbands and wives deal with things completely differently… (TI04)

4.3.1 Online Parent-to-Parent Support

All participants had experience of accessing a variety of online sites for support (Appendix 10). Support was generally accessed when the child was sleeping or during a quiet time.

4.3.1.1 Why Online Parent-to-Parent Support

Participants spoke of their initial reasons for venturing into online parent-to-parent support. For most, it was because the rareness of their child's condition meant that information, diagnosis and finding local support was/is not available. For these

participants, online support *"is the best thing that has ever come into my life"*, as further explained:

> *What to do when you get a diagnosis, you are given the worse possible information, it is very hard…you are told don't bother looking up the Internet, you can forget it you won't find another child with it, whereas I can turn around and safely say the Internet is the best thing that has ever come into my life and Facebook groups. I took comfort in the fact that somebody else with the same condition…we had nobody, I got on the Internet and found UNIQUE. No referral to nobody, no follow through, no referral to a paediatrician, received nothing in writing to this day on my child's diagnosis…* (TI07)

> *The day we got the diagnosis I went on Facebook and found one parent in the States, my child the only one diagnosed in Ireland…* (TI06)

Others spoke about needing to know *"you are not the only one"* as explained by two participants:

> *Desperate for information at the beginning…if you find you are the only one, you can't relax at all, find something where others are similar…* (TI04)

> *I am not alone with these experiences that there are people there that are going through the same as I am going through, to come away feeling that you are not alone…* (FG03)

4.3.1.2 Benefits of Online Parent-to-Parent Support

Some participants spoke about the benefits in engaging in online parent-to-parent support. As described by one participant:

> *Making contact with other families – huge difference, the system fobs you off …absolutely contact with other families gives me the strength mentally to keep going to know that I was right all along…I get a lot of support from reconfirming things with them- I can question are you finding this, I can check things to know where they are in their development to know what are the different possibilities….I was able to discuss with other parents what are the options…I was able to talk with another parent about, where they went and what worked for them and know that they have the situation in what works for the child, all finding the same problem.*

Just support, show pictures of how beautiful our [children] are, we love them even though society doesn't always treat you right, society doesn't know how to treat you at times and doesn't know how to look on these [children]. You walk out, go shopping you can see people giving odd looks to your child, it's lovely to have that connection with other parents… but the actual support it gives to a carer and to a family is massive, in helping I love my [child] I absolutely love [them] and enjoy [them]. Enjoyment has grown in a way because I have this connection with these other people the connection we have is just amazing because we don't know each other and we are all around the world and we are all so varied in our backgrounds and everything, by God we have such connections, we really do… (TI06)

4.3.1.3 Caution about Online Parent-to Parent Support

Some participants spoke about negative experiences in using parent-to-parent support websites, in particular, Facebook pages where they considered there were inappropriate postings. For example, they considered certain dialogue or videos by other parents were *"very negative".* Their concerns were generally with regard to the effects such posts might have on "new" parents, that is, those whose children perhaps are recently diagnosed. Participants considered such parents to be vulnerable at that time and posting inappropriate material could "*frighten them*". As one participant explained:

I think...you have to be very careful of what people post, because if you have a newly diagnosed parent going on to these Facebook pages and seeing people posting stuff that really isn't appropriate it can frighten them away and I think that is a big thing…it would be awful for a parent of a newly diagnosed child to come on and see a video of a chid having a seizure, it is not appropriate… (TI10)

Equally, parent found that some information on certain websites can be presented in a very negative way. Participants spoke about websites that have 'awful' stories:

In the beginning, they are not helpful, they are cold, when I looked at it first [account of story on child's condition] it frightened me a bit. As I get older I can now see the funny side of that, but in the beginning it is not helpful, it's cold and upsetting in the beginning… (FG03)

4.4 Current Sources of Online Parent-to-Parent Support

As reported in the previous RD-WIFI study (Nicholl *et al.* 2014), all participants used social media for support and to access information. Currently, when accessing websites, participants used smartphones while laptops were used less frequently. In some interviews, the issue of choosing to use smartphones over laptops resulted in further discussion, with some parents proposing that this could be a generational issue. This topic was not explored further.

All participants accessed Facebook pages for online support, while only some accessed websites. In this study, those who did access websites generally did so for specific information on condition specific websites. Participants viewed *"official"* websites as useful for diagnostic or medical information.

4.4.1 Why Facebook for Online Support

Participants explained why they use Facebook as their first choice for online support, as follows:

> *Everyone is on Facebook… open Facebook and you can look up anything with links to website if you want to go to it*… (TI08)

> *First place Facebook, if there is a Facebook page then there is something out there*… (TI05)

> *Facebook is my support system…I am on American, Australian sites, support groups internationally more locally I go with a [specific] group…I take what I need [in Ireland] nothing for rare disorders*…(TI07)

Participants chose Facebook pages over websites because they thought that websites generally did not capture the individual needs of the child and the variability or complexity of their condition. Whereas:

When you can ask a person on Facebook a question, they can answer you, somebody might have an idea of what you are talking about… (FG03)

It is people I find living with it, anyone who puts up something on a Facebook page, they are living with it, where if you google [on the internet] it is people who are going by a book, a text book, I realise with [my child's condition] just how much you can't go by a book. But, when you ask a person on Facebook a question, they can answer you, somebody might have an idea of what you are talking about… (FG02)

Equally participants felt that with some websites you do not usually have the ability to connect with someone directly. They believed that other Facebook users, who are usually living through the same experience, are open to exchanging information:

Facebook groups, there are a lot of groups on Facebook, where you can find out information…I suppose it is the free flow nature of it, the exchange of information between parents is phenomenal… (FG01)

They explained that if contacting someone via the 'contact' page of a website, "*it could take days before a reply is received"* whereas on Facebook, "so*meone will answer you that is the thing, someone will come back to you by the end of the day*… (FG03).

Some participants also spoke about how YouTube could be accessed through Facebook pages and they found these links useful in getting visuals or hearing someone speak about a condition.

4.5   Why an Irish Live Parent-to-Parent Support Platform

Participants stated that parents in Ireland need the support of a community with experiences similar to their own. They identified international supports as helpful and felt that due to the rareness of their child's condition these can, at this time, be their only source of support.

Some of the children reported on in this study may perhaps be the only child with that specific diagnosis in Ireland at the moment, with perhaps a few others in Europe

including the United Kingdom. In light of this, parents reported having to access online support in other English speaking countries such as Australia, Canada, New Zealand and also the United States of America. While these international sites offer support, it was felt that this support could be limited, as described:

UK and US are limited, so limited in support as they do not have the same experiences of diagnosis, treatment and public healthcare services… (TI08)

In Britain...Yes, they are of interest and of help. Minimal dialogue with other parents on these [because they do not share Irish experience of treatment] with dialogue about how the children are doing… (TI09)

In Ireland the […] website closed, now have to access UK based [website] but it has no parent-to-parent support on it…very hard to gain any information…very different to our needs,… (T105)

Also, as one parent explained:

[There is] no support from other Irish parents due to my child's condition, not helpful speaking with parents internationally… (TI04)

For participants, an Irish live parent-to-parent support platform would enable them to share issues that are the similar in terms of diagnosis, treatment, health and education systems, as explained:

On an Irish website [parents] would be able to talk with another parent in Ireland even though their child has a most rare condition which is unlikely to be shared with another child in Ireland. Children may not have the same condition but to be able to communicate with other parents even parents with a sick child, they could share experiences. Great to have something to go to in the country, talk about your child, discuss services in the country, which are lacking, that people outside the country wouldn't understand, so it will be great…(TI08)

[rare conditions]…the issues are the same…I know there is the Rare Connect but I think a central [Irish website], it is Irish and it has got Irish information about Irish systems like maybe the health system or the education system…and it is a

central point that feeds out to others, maybe it would be very like the SNP [special needs parent] association website…there is such a range, the issues are so broad, parents of children with life limiting conditions they know are not going to live, that is a whole set of issues but if it was one central point, this where I am at, I have a child with this condition, this is where I need to go…(FG01)

4.5.1 Meetings in Ireland

Participants spoke about the importance for them of meeting face-to-face with other parents. They said that while Facebook parent-to-parent support was extremely important for providing a sense of belonging, for sharing and receiving support they also need face-to-face encounters. The vast majority would like to have at least one annual family day. They would like some events such as coffee mornings and other opportunities as *"to meet up would be nice"* (T105). In almost all interviews this need emerged very strongly for participants, as explained:

> *Ways to meet more families, a family day to feel you belong, to meet other families, I would love to meet other families even families in similar situations we could support each other…* (TI06)

> *Once a year have a day for rare chromosomes, where parents and children can meet…* (TI07)

Participants felt that only an Irish website could promote such meetings and events:

> *Meet ups, events that you could actually go to, cos I find that sitting talking to another parent gives me great support…there is nowhere to go, nowhere, to be able to click on that website to see an event coming up that you could go…to meet with other parents, I think that is where you get your information from…sitting around having a coffee talking, like a chat group…* (FG02)

> *To get together…online is brilliant but it is not the same as meeting face-to-face… different groups on different conditions, important to have face-to-face meeting groups where you can meet up with people…* (TI09)

Such encounters and events when posted on platforms other than an Irish one, would have little relevance for the vast majority of participants, as explained:

> *Great to have something to go on to in the country, talk about your child, discuss services in the country which are lacking that people outside the country wouldn't understand, so it will be great…(TI08)*

Parents in Ireland identified a need for the support of a community with experiences similar to their own. Parents indicated that while they would like this support platform to have links to international organisations, information and other issues, it essentially would be Irish, supporting parents in Ireland and providing information about Ireland.

4.6 An Irish Website Proposal

> *An Irish website would be used for information and it should have Facebook, as this gives parents direct contact with each other. If Facebook is possible it should have a private page with restricted access and a public page for general access… (TI06)*

Participants supported the views expressed in the previous RD-WIFI study (Nicholl *et al.* 2014) in terms of the design, presentation and content of an Irish website for parents of children with a rare condition. Parents suggested that the site layout and content needs to be in plain English (NALA[1] approved) and cater for other languages to acknowledge that Ireland is a multicultural society. Overall, it should be easy for all individuals to use.

4.6.1 Expansions to Previous RD-WIFI (2014) Findings

Participants expanded on some of the previous RD-WIFI (Nicholl *et al.* 2014) findings. They believed that a Facebook page and live parent-to-parent support should be major feature on the website. The website and the live parent-to-parent support feature would

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[1] National Adult Literacy Agency.

need to be administered and monitored in line with current best practice. Links to 'official' sites should be included and importantly a link to the recently launched National Rare Diseases Office should be provided.

Events pages should also feature. Additionally, in terms of the site achieving an appealing layout it was said that:

> "…sometimes [sites] have too much on them, [when a site] is more applicable to you straight away, you are going to stay on it… (TI08)

Some participants expressed that they would like to see honest descriptions of conditions across the lifespan of the child and not solely focus on the young child, which is most commonly the case. They felt that parents need to be able to see, that it is possible for their child to transition from childhood to adulthood. They expressed a need for parents to be provided with honest, valid information about the condition as the child progresses, as explained:

> …a life span type of thing, it shouldn't be all focused on just young children…I think up to 18 things don't change, things change after 18, there are no great transition services from child to adult…they [children] grow up they don't suddenly get cured at 18…often parents of children when they do come to 18, they are unprepared… (FG01)

> …I would like to see more honest information about [conditions], that if a parent is finding it difficult that they can find new information, not be left as I was explaining…I am doing something wrong…, that people can look and see that there are [other] kids that are not managing…that the parents can feel more supported to enable them to talk…I am not a fan of hiding anything that can happen… (FG03)

Participants would like the website to present information about conditions by child's age, for example, information for expectant mothers who have a diagnosis prior to birth, information for parents of a young child, an adolescent and for an adult. As expressed:

I would like it to deal with all aspects of the particular conditions, be it difficult and not difficult, and all the age groups included from the very young to the older…life goes on… talk about it…(FG02)

Participants would also like the website to provide information on undiagnosed conditions and those that are unexplained as well as information on the latest international research that is available. Similarly, they would like information on clinical trials that are being conducted. In Ireland parents felt that they were not informed of clinical trials and were not invited to join them. Instead they find out when it is too late to take part and share a sense of being left behind.

Some spoke of developing a database containing parent details similar to, for example, UNIQUE. They would also like the website to have a process in place for parents to be contact 'expert' groups of parents, perhaps with a representative with whom parents would be able to discuss issues in an honest way. Others spoke of having a feature for healthcare professionals. This feature could, according to participants, be bi-directional, in that, education and or the acquisition of skills would be for both parents and healthcare professionals. Each group could learn from the other. As one participant explained:

... invariably doesn't it happen that we are telling the doctor or the nurse and we telling them, that you could say there is this really great website where you can go for information…that would be pretty unique…that the professionals could be accessing the parental expertise…that would set it apart…(FG03)

4.7   Proposal for an Irish Live Parent-to-Parent Support Platform

Participants would like the live parent-to-parent support to be provided via Facebook. As one parent suggested, "*Facebook if possible should have a private page with restricted access and a public page for general access*" (TI06). The private page would need to be secure with registered members only having access. The page would have to have an

administrator and be password protected where members needed to login in, as described:

> *…register, give profile, restricted to registered members…member login, can be anonymous under user name, have an administrator – don't want someone signing in – just those with genuine reasons…* (TI05)

It was considered that care would be needed in setting up this kind of support network in terms of creating profiles:

> *Creating a profile needs to be able to say what your child can do, need to talk to someone whose child is the same as mine, restricted to members, parents would need to register, give child's diagnosis and age. I would not dream of going on to it, if it was not set up that way…it would not be a support network if it is not set up like this…* (TI04)

Most spoke about the advantages of being able to post on Facebook, as explained:

> *Facebook page for all parents, if any parent has a question this can be posted. Very good where are kids at different stages, new babies, kids 18 coming through the system and some adults who can tell us how they felt growing-up. Communication about the older child gives you an insight to what might happen down the line, there might be a parent with a child that is 7/8 who is… and I can give advice to parents with babies for example what is the best… Also, we can share experience with say appointments you might have, or if a [doctor] is changing or say how you found them. Also you might meet by chance at the clinic when attending for an appointment, we get to know each other because the charity has a family day once a year…* (TI05)

And:

> *…on doctors or others health providers that members found good and information on their specialities…* (TI07)

While for the majority of participants open group forums were viewed as being an advantage, there were however, mixed views on this issue. Some participants also suggested having a separate Dad's and a sibling's forum. It was felt that such forums would have to be for parents sharing like-with-like experiences. Only invited people could join to talk about issues, for example, medical cards, but importantly care would need to be exercised when children and their conditions are being discussed. Most participants spoke about being cautious and having appropriate administration and monitoring of these forums. Some participants said they would only use a forum for "general information" and "finding out about new developments" but would not want to share information about their child. Some gave examples of these general discussions.

Certain services children are entitled to because of diagnosis for example July Provision (40 hours in the month of July) available only to children with autism and severe learning disability. Also children with Down Syndrome receive resource hours that children with other diagnoses do not receive. These resources should be made available on need and not just on diagnosis (TI09)

4.7.1 Proposed Irish Website Content

Participants would like pages on the website to be specific to the Irish context and others to provide national and international information. The section specific to the Irish context should include information on all relevant Irish services, such as health, social protection and education services and events in Ireland (Table 4.1). Parents also indicated that they would like information on the website to be categorised by child's age, for example, information for expectant mothers who have a diagnosis prior to birth, information for parents of a young child, an adolescent and an adult. The other webpages should provide information on rare conditions as well as details on research into those conditions (Table 4.2). The tables presented below represent participants' views.

Table 4.1: Content for Rare Conditions Irish Website

Content	Descriptions (according to participants)
Information for newly diagnosed	Information on where to go and on entitlements. Facility for members to write a piece and share with parents about how they felt at the time of diagnosis.
Events with links	Information on events, for example, coffee mornings and family days where parents could meet other parents of children with rare conditions.
Practical tips for finding appropriate clothing and equipment	With links to specific appropriate sites for items such as: shoes for grown children whose feet didn't develop; tops/vests suitable for PEG feeding; suitable bottles for babies with cleft lip palate etc.
Information on healthcare professionals	Healthcare professional with specialisms in rare conditions.
Information on services	• Health services, to include cross border services. • Education services • Revenue information • Social protection services, including entitlements.

Table 4.2: National and International Pages of Proposed Website

Content	Description (according to participants)
Information on rare conditions	To include treatment abroad schemes
Research	To include current clinical trials

4.7.2 Possible Links

Participants would like the website to provide only appropriate links, as explained,

> …if you try to put all the information on rare conditions it would be unmanageable have links to official websites… (FG01)

The table below presents participants' views on the types of links that parents would like (Table 4.3).

Table 4.3: Types of Possible Links on Proposed Website

Link Type	Information Type
National and international associations	Certain health conditions
National and international organisations	Research and clinical trials
Different websites for kids	Clinical trials recruitment
Information leaflets	Matching people/diagnosis

4.7.3 Examples of 'Good' Sites as Identified by Participants

Participants spoke about the various websites and Facebook pages they accessed (Appendix 10) and those sites/pages that they particularly favoured in terms of what was offered. The websites of the organisations presented in Table 4.4 below are those identified by participants.

Table 4.4: Websites Favoured by Participants

Organisation Name	Participants' View
"The Bubble Foundation (UK)" www.bubblefoundation.org.uk	Bright and positive
Chromosome Disorder Outreach CDO (US) www.chromosomedisorder.org	Has links to everything
Contact a Family www.cafamily.org.uk	Very clearly laid out, things well posted, easy to follow.
Climb www.climb.org.uk	Well presented, clearly written easy to follow information.
Encephalitis Global Inc. www.encephalitisglobal.org	Sends emails on 10 main threads everyday which says here is what you have missed to-day. No need to login. It has two Facebook pages, one for caregivers and one for survivors.
Epilepsy Ireland www.epilepsy.ie	Positive, it is for everyone, Irish and easy to follow.
GRDO – Genetic and Rare Disorders Organisation www.grdo.ie	Clear, informative, Irish and international information.
RareConnect www.rareconnect.org	Has everything.
SNPA Special Needs Parent Association www.specialneedsparents.ie	Superb website in every way and its Irish.
SWAN UK Syndromes without a name www.undiagnosed.org.uk	A good website with great bright photos and very easy to follow.

Chapter Five: Discussion

5.1 Introduction

The primary purpose of this follow-up descriptive exploratory study was to further investigate the development of an Irish website for parents of children with rare conditions specifically with regard to the development of a live parent-to-parent support platform feature on that website. The previous study, *Rare Diseases Web-Information for Families in Ireland* study *(RD-WIFI)* (Nicholl *et al.* 2014) identified that the site be easily accessible, live, up-to-date, disability friendly, interactive and have links to national and international organisations. In relation to content, it should be presented in plain understandable language in English and Irish, be reliable and credible, balanced in its presentations, 'not just the science but also real life stories' and provide up-to-date research information.

One of the RD-WIFI reports (Nicholl *et al.* 2014) most compelling findings was the identification of the need for a live parent-to-parent support platform feature to be included in the design of the proposed website. Building on this, the current study set out to further investigate, with parents, the concept of a live parent-to-parent support platform feature on that website. The strategy of involving proposed users in the exploration is strongly supported by Paterson *et al.* (2013), who found that in the development of most online social support interventions the target population was excluded, resulting in interventions that did not reflect the needs of that population.

This study is timely in that the National Rare Diseases Office, a development of the National Rare Disease Plan (2014), was launched in June 2015 (Varadkar 2015).

5.2   Discussion

5.2.1 Parent-to-Parent Support for Parents of Children with Rare Conditions

All participants in this study had accessed parent-to-parent support. According to Pelentsov *et al*. (2015) the importance of support for this population is because rare conditions may not be identified during pregnancy or at birth and do not usually have support pathways in place. For this study's participants, the need for sharing experiences and learning from other parents was important in developing their understanding of their child's condition and in assisting them in caring for their child. They also sought support to reduce their sense of isolation in order to feel less alone and to find other parents who shared similar situations (Ainbinder *et al.* 1998, Skinner & Schaffer 2006, Ayme *et al.* 2008, McGarvey & Hart 2008, Roche & Skinner 2009, Gundersen (2011), Kingsnorth *et al.* 2011, Anderson *et al.*2013, Paterson *et al.* 2013, Nicholl *et al.* 2014, Glenn 2015, Pelentsov *et al.* 2015, Irish Autism Action 2015). Participants felt it was not necessarily important that their children shared the same diagnoses, as they believed that parents of children with rare conditions face many similar issues, for example, difficulty with diagnosis, lack of skilled healthcare professionals, effective treatment options and a limited resourced health service (Ainbinder *et al.* 1998, Anderson *et al.* 2013).

5.2.1.1 Online Parent-to-Parent Support

All participants had experience of accessing online parent-to-parent support communities (Tozzi *et al.* 2013). For the majority of participants, due to the rareness and in some cases the extreme rareness of their child's condition, parent-to-parent support was difficult to access in Ireland. Therefore, the Internet (Oprescu *et al.* 2013) available 24/7 provided them with the opportunity to widen their search and access information from international sources (Anderson *et al.* 2013, Niela-Vilén *et al.* 2014, Pelentsov *et al.* 2015). They conducted international searches because some of the children's conditions may perhaps be the only one diagnosed in Ireland, with perhaps

few others in Europe including the United Kingdom. To find support, participants accessed sites from other English speaking countries such as Australia, Canada, New Zealand and also the United States of America (Anderson *et.al,* 2013). Participants used international online resources for a variety of reasons, to seek information about their child's condition, to ask questions (Han and Belcher 2001, Tuffrey & Finlay 2002, Kingsnorth *et al.* 2011, Niela-Vilén *et al.* 2013, Nieuwboer *et al.* 2013, Oprescu *et al.* 2013, Nölke *et al.* 2015), to make contact with other parents, and to talk about their children with other parents who they believed would understand (Beall 2001, Anderson *et al.* 2013, Jung Oh *et al.* 2014. Wittmeier *et al.*2014, Glenn 2015, Pelentsov *et al.* 2015). While participants found these international supports to be helpful they also viewed them as limited.

5.2.2 Why an Irish Social Networking Parent-to-Parent Support Site

All participants viewed an Irish 'live' social networking site (SNS) as essential for providing parent-to-parent support. They felt that they, as parents living in Ireland, need the support of a community with experiences similar to their own (Paterson *et al.* 2013, Pelentsov *et al.* 2015). They viewed that this platform would enable them to share similarities around issues such as diagnosis, treatment and the health and education systems. They held that while this platform would be Irish, supporting parents in Ireland and providing Irish information.

A key finding was the view that Facebook support, while very important, was not sufficient, participants' also required face-to-face meetings (Oprescu *et al.* 2013). In almost all interviews, face-to-face meeting events were viewed as essential to their support needs. For participants, meetings and events publicised on non-Irish live network sites had little relevance for them. They thought that an Irish SNS could serve to promote face-to-face meetings in Ireland, including at least one annual family day.

The vast majority would like the SNS to promote at least one annual family day, similar to those held by organisations such as the Jack and Jill Children's Foundation. They would also like other events such as coffee mornings and other meeting opportunities to be advertised on the site to meet other parents of children with rare conditions. They viewed all such face-to-face meeting events as fundamental to their support needs.

5.2.3   Future Irish Social Networking Parent-to-Parent Support Site

Findings from this study support those from Nicholl *et al.* (2014) with regard to its call for an Irish website for parents of children with rare conditions. In particular Nicholl *et al.* (2014) findings regarding the layout and content of the proposed website, specifically about the need for interactivity, relevant content, the involvement of healthcare professionals were strongly supported (Hand *et al.* 2013, Glynn *et al.* 2013, Oprescu *et al.* 2013). In addition participants expressed the view that the proposed website should be linked to official sites and most importantly, it should provide a link to the recently launched National Rare Diseases Office.

This study expands on findings from Nicholl *et al.* (2014) to include the provision of a live parent-to-parent SNS feature on the website. Both the website and the SNS feature should be administered and monitored in line with current best.

Participants stated that live parent-to-parent support via a SNS, namely, Facebook would be their preference. It was suggested that there could be a private Facebook page with restricted access for registered members and a public page for general access. They stressed the need for care to be taken in setting up the SNS with regard to developing features for creating account profiles. Restricted access to members only would have to be ensured with registration, for example, proving details about their child's diagnosis and age being required by members to login.

Group forums were considered to be an advantage, places where people can share similar experiences, with some parents also suggesting that a Dad's and a sibling's forum would be useful. It was emphasised that care would need to be exercised when talking about children and their conditions and when inviting people to join the forums and group discussions.

5.2.3.1 Website Content

This study further expanded on the website content preferences set out in the RD-WIFI report (Nicholl *et al.* 2014). Some parents stated that they need to be able to see that it is possible for their child to transition from childhood to adulthood. Therefore they would like to see honest descriptions of conditions across the lifespan of the child rather than the sole focus on the young child. They wanted parents to be provided with honest, valid information about the condition as the child progresses. Participants would like information on the website to be categorised by age of the child, for example, information for expectant mothers who have a diagnosis prior to birth, information for parents of a young child, an adolescent and an adult. Also, they would like information on undiagnosed conditions and those that are unexplained (for example, specific symptoms) to be provided along with news on the latest international research. Similarly, they would like to be provided with information on clinical trials that are being conducted. They thought that in Ireland parents are not informed about clinical trials and are not invited to join them, they find out when it is too late to take part and as a result feel they are being left behind. Some parents spoke of developing a database containing parent details similar to Unique. Parents also suggested that the proposed website should have a system in place for parents to be able to contact 'expert groups' of parents and further suggested that an events page should also be a feature available on the proposed website and on the SNS feature.

Participants would like webpages on the website and the SNS that are specific to the Irish context as well as webpages that provide international information. For the 'Irish'

webpages, information should be provided on all relevant Irish services, for example, health, social protection and education services and events in Ireland (see Table 4.1). The international webpages should provide information and news on rare conditions and research into those conditions (see Table 4.2). The website should also provide links to appropriate relevant organisations (see Table 4.3) as well sites that participants particularly favoured in terms of what they offered (see Table 4.4).

5.2.3.2 Information and Communication Technology

In designing a future Irish parent-to-parent support SNS it will be essential to have knowledge of the information and communication technology (ICT) skills and preferences of the proposed user. All participants in this study used ICT including smartphones (Hand *et al.*2013, Glynn *et al.* 2013, Rudi *et al.* 2015, Weckler 2015) with computers and laptops being used to a lesser extent (Glynn *et al.* 2013, Weckler 2015).

Facebook is often the first choice for many people accessing SNSs *(Ellison et al. 2007)*, this was also the case with this study. Websites were accessed less for social networking purposes, a findings that differs from other recent studies (Dworkin *et al.* 2013, Paterson *et al.* 2013, Jung Oh *et al.* 2014, Nicholl *et al.* 2014). Facebook pages were accessed for support and information whereas websites were accessed only to gather information. In general, specific conditions' websites were accessed, as participants viewed 'official' websites as useful for obtaining diagnostic and medical information. In seeking support, participants chose Facebook over websites because they felt that websites do not capture the individual needs of the child, the variability and complexity of their condition. They also felt that websites generally do not offer the ability to connect directly with someone, with answers to queries often taking several days and then they were considered to be "text book" replies. Alternatively, Facebook provided access to other Facebook users who were usually living through the same experience and provided rapid responses.

In summary, participants overall preference was for the proposed website to provide a live social networking platform, preferably Facebook, and the website should be designed to be smartphone/computer/tablet-friendly.

5.3   Conclusion

This study supports and builds on the findings from the previous RD-WIFI study (Nicholl *et al.* 2014) for the development of an innovative Irish website for parents of children with rare conditions. It further identified participants' need for an Irish smartphone/computer/ tablet-friendly live SNS feature in order to provide parent-to-parent support. Participants viewed that they, as parents living in Ireland, need the support of a community sharing similar experiences to their own. They held that while this live networking site would have international links, it would be Irish, supporting parents in Ireland and providing Irish information.

5.4   Limitations

5.4.1 The Sample
The sample comprised of parents of children with rare conditions.

5.4.2 Data Collection

The sample was limited to parents of children with rare conditions who were recruited by the Saoirse Foundation, acting as gatekeeper. Initially the study sought to hold nationwide focus groups across four centres. However, following difficulties in obtaining sufficient numbers, only one focus group was held. Further data were collected via telephone interviews.

5.4.3 The Findings

The study's findings reflect only the views of those parents who chose to participate in the study.

5.5   Recommendations

This study recommends the provision of an Irish website for parents of children with rare conditions as proposed by Nicholl *et al.* (2014). In addition, this website should contain a live parent-to-parent social networking site (SNS) feature.

➢ Design of the website needs to consider the following:

- o All information to be provided by trusted sources.

- o The site should be smartphone/computer/tablet-friendly.

- o Provision of a live parent-to-parent SNS feature which would:
  - be administered and monitored in line with best practice
  - include an events element promoting parent and family meetings including an annual family day.

➢ Links on the website to include:
- Irish official websites for health, education, welfare and social services
- The National Rare Disease Office
- Irish rare condition specific organisations
- Irish organisations for parents, families and children with special needs

- official international websites for rare conditions and other health related websites

- international rare conditions specific organisations.

➢ Development of the website should:

- have continued involvement of parents of children with rare conditions

- take cognisance of potential users' level of ICT skills and preferences

- benchmark the design, layout and content against other appropriate first rate Irish and international websites.

➢ Future research into the:

o level of ICT skills and preferences of potential users

o role of healthcare professionals in the development and provision of a live parent-to-parent SNS feature

o inclusion of 'expert' parents in the development and provision of a live parent-to-parent SNS feature

o inclusion of a support feature for siblings.

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Appendix 1: Letter of Invitation to Focus Group

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

SAOIRSE foundation
making positive life impacts for sick children

May 2015

Dear Sir/Madam,

My name is Honor Nicholl, I am a registered children's nurse and Assistant Professor in the School of Nursing and Midwifery, Trinity College Dublin (TCD). On behalf of Saoirse Foundation and Trinity College Dublin I and my colleagues are pleased to announce an addition to the proposed website for parents of children with rare conditions. This addition is the development of the website's *parent-to-parent support,* a recommendation from parents who took part in the study *'Web Information for Families of Children with Rare Diseases'* (2014).

I am contacting you as a parent of a child with a rare condition. Your experiences of the need for parent-to-parent support and information for parents who are caring a child with a rare condition are relevant to this research study in the development of *parent-to-parent support.*

We would like your input to this study and wish to invite you to participate in one of our focus groups which will be held in: Dublin 15th June, Tullamore 17th June, Galway 23rd June and Cork 25th June (venues to be confirmed). A payment of up to €40 will be given to assist you in travel expenses and light refreshments will be available at the venue.

To participate, you will need to contact us and sign a consent form on the day of the focus group. With your permission the focus group interview will be audio recorded, you may have access to the summary of the focus group interview, if you wish. This study has been granted ethical approval from the School of Nursing & Midwifery Trinity College Dublin and has been kindly funded by The Irish Research Council.

Enclosed is information about the study that I would like you to consider. If you would like any further information, or if anything in the documents is unclear, **please contact Dr Catherine Tracey by email:** traceyca@tcd.ie or Dr Aileen Lynch by telephone: 01 896 8571 and they will be happy to discuss the study further with you.

Next steps:
1. Please read the enclosed participant information sheet and participant consent form.
2. Decide if you wish to take part in the study or not.
3. If you wish to take part, please let us know by contacting either Catherine by email: traceyca@tcd.ie or Aileen by telephone: 01 896 8571.

We would be really grateful for your input and look forward to further contact with you in relation to this study.

Yours sincerely,

Dr Honor Nicholl, School of Nursing and Midwifery, Trinity College Dublin, Dublin 2.

Appendix 2: Participant Information Sheet-Focus Group

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

SAOIRSE foundation
making positive life impacts for sick children

PARTICIPANT INFORMATION SHEET
Title of study: Rare conditions Irish website – *parent-to-parent support*

1.   Further information about the study: Parents of children who require complex care have needs for support and information, and online parent-to-parent support is a valuable resource for parents. The purpose of this study is to build on the findings from the previous collaborative Trinity College Dublin and Saoirse Foundation study *'Web Information for Families of Children with Rare Diseases'* (RD-WIFI) study (2014) for an addition to the proposed website for parents of children with rare conditions. This addition is the development of the website's ***parent-to-parent support,*** a recommendation from parents who took part in the study.

The objectives of the study are to:
- build on the previous study's findings which recommended a live parent-to-parent support platform,
- determine where parents currently acquire online parent-to-parent support,
- determine the nature of the parent-to-parent support that is being sought by parents online,
- identify any gaps in terms of current online parent-to-parent support,
- determine what are the most important features, support and information a parent-to-parent online platform should include/provide.

2.   Procedures: You have been invited to participate because, as a parent of a child with a rare condition, your experiences of the need for support and information for the child you care for are relevant. Other parents of children with rare conditions have also been invited.

If you decide to participate in this study you are invited to attend a focus group interview with other parents. Each focus group will take approximately 60-90 minutes and with your permission will be audio recorded. If you wish, you can have a copy of the summary of the outcome of the focus group.
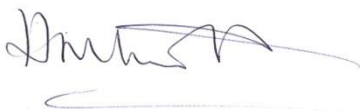
There will be four focus groups and these will take place in Dublin (15th June), Tullamore (17th June), Galway (23rd June) and Cork (25th June). A payment of up to €40 will be given to assist you in travel expenses and light refreshments will be available at the venue.

To participate you will need to contact Dr Catherine Tracey or Dr Aileen Lynch by contacting Catherine at email: traceyca@tcd.ie or Aileen by telephone: 01 896 8571.

3.   Benefits: While there may be no direct benefit to you from this study, it is anticipated that the findings will assist in the development of a live parent-to-parent support platform on the first Irish website for parents of children with rare conditions.

4. **Risks:** It is not anticipated that there will be any adverse outcome for you. Should you become upset during the focus group interview, you may withdraw (if you wish) at that stage and you will be provided with information about appropriate support services. There will be no impact if you choose not to contribute.

5. **Exclusion from participation:** *You cannot participate in this study if any of the following are true*: You are a parent of a child with a rare condition who, having been invited, **has not agreed** to participate in the study.

6. **Confidentiality:** Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the study group. All information cited in the report or any future publications arising from this study will not identify you. All information/data will be held in a secure locked cabinet accessible only by the researchers and all computerised data will be stored on a password protected computer only accessible by the research team.

7. **Compensation:** This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

8. **Voluntary Participation:** If you decide to volunteer to participate in this study, you may withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not give up any benefits that you had before entering the study.

9. **Stopping the study:** You understand that the investigators may withdraw your participation in the study at any time without your consent.

10. **Permission:** This research study has received ethical approval from the School of Nursing & Midwifery, Trinity College Dublin.

11. **Funding**: This study has been kindly funded by the Irish Research Council.

12. **Further information:** You can get more information or answers to your questions about the study, your participation in the study, and your rights from Dr Catherine Tracey or Dr Aileen Lynch. Please contact Catherine at: traceyca@tcd.ie or Aileen on telephone: 01 896 8571.   If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once. You agree that anonymised data from the study may be stored and used in future related studies without further consent being sought from you.
I realise that this may be a busy time for you and I really appreciate you taking the time to read this information sheet. Thank you.

Yours sincerely,

Dr Honor Nicholl, School of Nursing and Midwifery, Trinity College Dublin, Dublin 2.

Appendix 3: Participant Information Sheet-Telephone Interview

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

SAOIRSE foundation
making positive life impacts for sick children

PARTICIPANT INFORMATION SHEET

Title of study: Rare conditions Irish website – *parent-to-parent support*

1. **Further information about the study:** Parents of children who require complex care have needs for support and information, and online parent-to-parent support is a valuable resource for parents. The purpose of this study is to build on the findings from the previous collaborative Trinity College Dublin and Saoirse Foundation study *'Web Information for Families of Children with Rare Diseases'* (RD-WIFI) study (2014) for an addition to the proposed website for parents of children with rare conditions. This addition is the development of the website's ***parent-to-parent support,*** a recommendation from parents who took part in the study.

The objectives of the study are to:
- build on the previous study's findings which recommended a live parent-to-parent support platform,
- determine where parents currently acquire online parent-to-parent support,
- determine the nature of the parent-to-parent support that is being sought by parents online,
- identify any gaps in terms of current online parent-to-parent support,
- determine what are the most important features, support and information a parent-to-parent online platform should include/provide.

2. **Procedures:** You have been invited to participate because, as a parent of a child with a rare condition, your experiences of the need for support and information for the child you care for are relevant. Other parents of children with rare conditions have also been invited.

If you decide to participate in this study you are invited to a telephone interview. Telephone interviews will take place in the week beginning 6th July. Each interview will take approximately 15/20 minutes and will be audio recorded.

You will need to give your consent to participate. Your consent will be confirmed at the time of the interview.

A copy of the summary of the interviews will be available, if you wish.

A payment of up to €40 will be given to assist you with any expenses incurred.

To participate you will need to contact Dr Catherine Tracey or Dr Aileen Lynch by contacting Catherine at email: traceyca@tcd.ie or Aileen by telephone: 01 896 8571.

3. **Benefits:** While there may be no direct benefit to you from this study, it is anticipated that the findings will assist in the development of a live parent-to-parent support platform on the first Irish website for parents of children with rare conditions.

4. **Risks:** It is not anticipated that there will be any adverse outcome for you. Should you become upset during the telephone interview, you may withdraw (if you wish) at that stage and you will be provided with information about appropriate support services. There will be no impact if you choose not to contribute.

5. **Exclusion from participation:** *You cannot participate in this study if any of the following are true*: You are a parent of a child with a rare condition who, having been invited, **has not agreed** to participate in the study.

6. **Confidentiality:** Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the study group. All information cited in the report or any future publications arising from this study will not identify you. All information/data will be held in a secure locked cabinet accessible only by the researchers and all computerised data will be stored on a password protected computer only accessible by the research team.

7. **Compensation:** This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

8. **Voluntary Participation:** If you decide to volunteer to participate in this study, you may withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not give up any benefits that you had before entering the study.

9. **Stopping the study:** You understand that the investigators may withdraw your participation in the study at any time without your consent.

10. **Permission:** This research study has received ethical approval from the School of Nursing & Midwifery, Trinity College Dublin.

11. **Funding**: This study has been kindly funded by the Irish Research Council.

12. **Further information:** You can get more information or answers to your questions about the study, your participation in the study, and your rights from Dr Catherine Tracey or Dr Aileen Lynch. Please contact Catherine at: traceyca@tcd.ie or Aileen on telephone: 01 896 8571. If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once. You agree that anonymised data from the study may be stored and used in future related studies without further consent being sought from you.

I realise that this may be a busy time for you and I really appreciate you taking the time to read this information sheet. Thank you.

Yours sincerely,

Dr Honor Nicholl
School of Nursing and Midwifery, Trinity College Dublin, Dublin 2.

Appendix 4: Letter of Invitation for Telephone Interview

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

SAOIRSE foundation
making positive life impacts for sick children

June 2015

Dear Sir/Madam,

My name is Honor Nicholl, I am a registered children's nurse and Assistant Professor in the School of Nursing and Midwifery, Trinity College Dublin (TCD). On behalf of Saoirse Foundation and Trinity College Dublin I and my colleagues are pleased to announce an addition to the proposed website for parents of children with rare conditions. This addition is the development of the website's *parent-to-parent support,* a recommendation from parents who took part in the study *'Web Information for Families of Children with Rare Diseases'* (2014).

I am contacting you as a parent of a child with a rare condition. Your experiences of the need for parent-to-parent support and information for parents who are caring a child with a rare condition are relevant to this research study in the development of *parent-to-parent support.*

We would like your input to this study and wish to invite you to participate in one of our telephone interviews which will be held in week commencing 6th July 2015. A payment of up to €40 will be given to assist you in any expenses incurred.

This study has been granted ethical approval from the School of Nursing & Midwifery Trinity College Dublin and has been kindly funded by The Irish Research Council. With your permission the telephone interview will be audio recorded, you may have access to the summary of the interviews, if you wish. At the time of the interview, your consent to participate will be confirmed and audio recorded before the interview begins.

Enclosed is information about the study that I would like you to consider. If you would like any further information, or if anything in the documents is unclear, please contact Dr Catherine Tracey by email: traceyca@tcd.ie or Dr Aileen Lynch by telephone: 01 896 8571 and they will be happy to discuss the study further with you.

Next steps:
1. Please read the participant information sheet.
2. Decide if you wish to take part in the study or not.
3. If you wish to take part, please let us know by contacting either Catherine by email: traceyca@tcd.ie or Aileen by telephone: 01 896 8571.

We would be really grateful for your input and look forward to further contact with you in relation to this study.

Yours sincerely,

_____
Dr Honor Nicholl,
School of Nursing and Midwifery, Trinity College Dublin, Dublin 2.

Appendix 5: Participant Consent Form

PARTICIPANT CONSENT FORM

TITLE OF STUDY: **Rare conditions Irish website –** *parent-to-parent support*

PRINCIPAL INVESTIGATOR: Dr Honor Nicholl

BACKGROUND: Parents of children who require complex care have needs for support and information, and online parent-to-parent support is a valuable resource for parents. The purpose of this study is to build on the findings from the previous collaborative Trinity College Dublin and Saoirse Foundation study *'Web Information for Families of Children with Rare Diseases'* (RD-WIFI) study (2014), for an addition to the proposed website for parents of children with rare conditions. This addition is the development of the website's *parent-to-parent support,* a recommendation from parents who took part in the 2014 study.

This study has been granted ethical approval from the School of Nursing & Midwifery Trinity College Dublin and has been kindly funded by The Irish Research Council.

The objectives of the study are to:
1. build on the previous study's findings which recommended a live parent-to-parent support platform,
2. determine where parents currently acquire online parent-to-parent support,
3. determine the nature of the parent-to-parent support that is being sought by parents online,
4. identify any gaps in terms of current online parent-to-parent support,
5. determine what are the most important features, support and information a parent-to-parent online platform should include/provide.

PARTICIPATION WILL INVOLVE
- Your consent to participate in the telephone interview will be confirmed and audio recorded at the time of the interview, before the interview starts.
- The interview will take approximately 15/20 minutes and with your permission will be audio recorded.
- All information collected in the interview will be treated confidentially. Your identity and that of your child will remain confidential at all times and will not appear in any related publications.
- You will be offered a copy of the summary of the outcome of the interview, if you wish.

DECLARATION by PARTICIPANT

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I agree that anonymised data from the study may be stored and used in future related studies without further consent being sought from me. Data from the study will not be used in future unrelated studies without further specific permission being obtained. I understand that I may withdraw from the study at any time.

AT TIME OF INTERVIEW

Participant's consent will be confirmed and audio recorded

PARTICIPANT'S Name	Consent Given
Contact Details	Date

Statement of researcher's responsibility

I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and have fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHER'S Signature	Date

Appendix 6: Demographic Sheet

**RD-WEB P2PS: Parent-to-Parent Support
Code:**

1. **May I ask a few brief questions about yourself please? Are you the child's:**
   - ☐ Father
   - ☐ Mother
   - ☐ Legal guardian

2. **What is your age?**
   - ☐ 18 to 34
   - ☐ 35 to 49
   - ☐ 50 to 64
   - ☐ 65 to 79
   - ☐ 80 or older

3. **What location BEST describes where you live?**
   - ☐ City
   - ☐ Town
   - ☐ Village
   - ☐ Rural

4. **What is your HIGHEST level of education?**
   - ☐ Primary school
   - ☐ Secondary school
   - ☐ Vocational training
   - ☐ Undergraduate degree
   - ☐ Postgraduate degree

5. **Are you:**
   - ☐ Employed full-time
   - ☐ Employed part-time
   - ☐ Self-employed
   - ☐ Child/children's main carer
   - ☐ A homemaker
   - ☐ A student
   - ☐ Unemployed
   - ☐ Other (please specify)

6. **What age is your child?**

7. **Is your child male or female?**
   - ☐ Male
   - ☐ Female

8. **If your child has a diagnosis, please indicate your child's condition and their age when diagnosed.**

Appendix 7: Literature Search

Defining the Key Concepts:

Three key concepts were defined for the searches for the parent-to-parent support through the Internet for the literature review. These terms were agreed through discussions by the team. Life limiting illness, genetic illnesses and hereditary conditions, conditions and conditions were all specified as key areas of interest. Due to the high number of individualised or single case examples of life threatening illnesses the terminology was kept broad rather than listing individual conditions or conditions.

The second concept selected was parents. The third concept identified was the Internet or any use of smart device technology. Social media resources were also included in the search criteria. This concept was expanded to include palliative care and also hospice care. (A full list of search terms can be found below).

Development of Search Terms

Once the initial concepts were defined by the group the Librarian used a number of techniques to try and capture the relevant search terms relating to each concept. Initial scoping searches were run in both PubMed and CINAHL. These searches provided a list of synonyms provided by MeSH terms and CINAHL headings. The scoping search results were also manually scanned to look for additional author keywords as provided in the article bibliographic records. The Librarian used explicit searching of pluralisation, rather than use truncation in the searches due to the variable way in which databases can treat truncated terms. Once a set of search terms was developed, the results were sent back to the team for review. When the definitive list of terms was agreed the Librarian proceeded to run a series of systematic searches using the same terminology and the same search criteria. The team agreed that no further filters should be applied to the terms supplied in the appendix.

Eight key databases were selected for searching. Well known health databases like PubMed, CINAHL, MEDLINE, and ProQuest Nursing & Allied Health were initially targeted for searching. Additional searches were run in Academic Search Complete (a cross disciplinary database), Social Science Index, and the British Nursing Index. This database spectrum ensured wide coverage of the literature ranging from journal articles to conference proceedings and monographs.

Running the Searches:

Each of the three concepts agreed set of search terms were run across the eight databases. Each concept was searched individually and then finally combined with the other concepts using the advanced search function within each of the databases. Table A shows the list of the results based on each of the searches and the final combined number. After running the searches and combining the terms the database searches returned a total of 368 articles.

Endnote:

An Endnote Library was set up to manage the results of the searches. Smart Groups were created to manage the search results. A smart group, in Endnote, is created by a user

with certain searching criteria to dynamically update groups as existing references are edited and new references are added to the library. It is similar to a canned search. Smart groups allowed a quick way to show the origins of search results and also to show the number of original and duplicate articles once the Library was populated. Smart groups were used to identify which of the databases the articles had originated. This helped making it easier to find duplicates.

Managing the search Results:

Once all the searches were completed in each database the results were exported into the Endnote Library. Using the find full text function in Endnote, 142 full text pdfs were identified and attached to their bibliographic records. An additional 11 links to the full text within the Endnote library were also embedded within the record. This resulted in a balance of 158 articles which would need to be manually tracked down by the team.

De-duplication of Results:

Endnote has an automated de-duplication process, this identified 88 duplicates. A second manual de-duplication exercise which found an additional duplicate record. This resulted in a total of 33 duplicate articles within the initial 368 results. As a result of the deduplication process the final number of results left for analysis was 257 articles. To ensure that a duplicate was clearly defined from the original article a series of codes were created and used in the custom field. "original" indicated an original article "duplicate" indicated a duplicate. A smart Group was then set up to weed the custom group into their specific result sets. This enabled the Endnote Library to auto-populated the smart groups which clearly state "Original Article" or "Duplicate Article".

Table A: Summary of literature search

Terms / Database	PubMed	CINAHL	Academic Search Complete	PsycInfo	BNI	MEDLINE	ProQuest Nursing & Allied Health Source TI/AB	Social Sciences Full Text (H.W. Wilson)
Life limiting illness	174311	59,522	81,349	15,838	2099	173,669	34550	2,772
Parent	511074	102,827	503,425	279,608	11964	458,106	115311	47,690
Internet	113111	94,389	597,266	57,916	2840	88,709	38885	25,654
Combine	**75**	**121**	**58**	**14**	**4**	**59**	**34**	**3**

Search Terms:

Concept 1: Life limiting illness

PubMed: Rare Conditions OR Neglected conditions

CINAHL SH: (MH "Critical Illness") OR (MH "Catastrophic Illness") OR (MH "Genetic Conditions, X-Linked+") OR (MH "Hereditary Conditions+")

Free Text Language: "Rare Condition" OR "Rare Conditions" OR "Rare Condition" OR "Rare Conditions" OR "Rare condition" OR "Rare conditions" OR "ultra Rare Condition" OR "ultra Rare Conditions" OR "ultra Rare Condition" OR "ultra Rare Conditions" OR "ultra Rare condition" OR "ultra Rare conditions" OR "ultra-rare Condition" OR "ultra-rare Conditions" OR "ultra-rare Condition" OR "ultra-rare Conditions" OR "ultra-rare condition" OR "ultra-rare conditions" OR "Orphan Conditions" OR "Orphan Condition" OR "life-limiting conditions" OR "life limiting conditions" OR "life limiting condition" OR "life-limiting condition" OR life-threatening OR "life threatening" OR "Life threatening conditions" OR "Life-threatening conditions" OR "Life threatening condition" OR "Life-threatening condition" OR "terminal illness" OR "terminal illnesses" OR "life-limited" OR "life limited" OR life-sustaining OR "life sustaining" OR "sustaining life" OR "Life Limiting Illnesses" OR "Life-Limiting Illnesses" OR "Life Limiting Illness" OR "Life-Limiting Illness" OR "Genetic Condition" OR "Genetic Conditions" OR "Genetic Condition" OR "Genetic Conditions" OR "Genetic condition" OR "Genetic conditions" OR "Inborn Genetic Condition" OR "Inborn Genetic Conditions" OR "Single-Gene Defects" OR "Single Gene Defects" OR "Single-Gene Defect" OR "Hereditary Conditions" OR "Hereditary Condition" OR "Critical Illness" OR "Critical Illnesses" OR "critically ill" OR "Catastrophic Illness" OR "Catastrophic Illnesses"

Concept 2: Parents

PubMed: Parents OR single parent

CINAHL: Parents +

Free Text: Parent OR parents OR "Parenthood Status" OR Step-Parents OR "Step Parents" OR "Step-Parent" OR "Stepparent" OR Stepparents OR mother OR mothers OR mother's OR Mum OR Mums OR Dad OR Dads OR Daddy OR Daddies OR Daddy's OR "parent-to-parent" OR "parents to parents" OR parenting OR parental OR "Parent, Single" OR "Parents, Single" OR "Single Parents" OR "Single Stepparent" OR "Single Stepparents" OR "Stepparent, Single" OR "Stepparents, Single" OR "Single Step-Parent" OR "Single Step Parent" OR "Single Step-Parents" OR "Step-Parent, Single" OR "Step-Parents, Single"

Concept 3: Internet

PubMed: Internet OR Social Media OR Blogging

CINAHL: Social Media OR Blogs OR Internet

Free Text Language: Internet OR Internets OR World Wide Web OR www OR Twitter OR Messaging OR skype OR Facebook OR facetime OR skyping OR tweet OR tweets OR tweeting OR texting OR blog OR blogs OR blogging OR "social media" OR SMS OR Instagram OR flikr

OR "social Mediums" OR Wikipedia OR wiki OR wikis OR YouTube OR forums OR "online forum" OR microblogging OR "social forum" OR "Internet forum" OR "Internet forums" OR podcasts OR podcast OR screencast OR screencasts OR crowdsourcing OR crowd-sourcing OR "crowd sourcing" OR Pinterest OR Facebooking OR google OR "search engine" OR "search engines" OR browser OR browsers OR screen-cast OR screen-casts OR "social media" OR "social medias" OR "media, social"

Appendix 8: RD-WEB P2PS Parent-to-Parent Support FOCUS GROUP

Interview Format and Guide

The purpose of the focus group interviews are to further explore and make recommendations for the information needed to devise a live platform for parent-to-parent support in the first Irish rare condition website for parents involved in the care of children with rare conditions.

The focus groups will explore relevant areas to the research study and has been informed by findings from the recent collaborative TCD / Saoirse Foundation study: *'Web Information for Families of Children with Rare Diseases'*.

FORMAT OF FOCUS GROUP

- Welcome & introductions
- Participants will be given the information pack (information sheet, consent form and demographic questionnaire) and asked to complete the demographic questionnaire and sign the consent form if they feel happy to do so.
- Initiation of focus group interview
- Recapping on main points:
  - The study has TCD ethical approval. Participation is voluntary and you can withdraw from the interview at any time with no repercussions. Your identity will not be revealed in any way. Your name will remain anonymous including in all published information emanating from the study. All data are confidential. All data are for research purposes only.
  - The focus group interview with your permission will be tape recorded and notes will be taken to ensure there is an accurate record of the proceedings.
  - There are no right or wrong answers to the questions posed, the main objective is that the group can share their valuable experiences and opinions.
  - You may choose to respond or not to questions.

- o Any participant questions will be answered at this time.
- Interview ground rules:
    - o Request that one person speak at a time
    - o When speaking use pseudonym
    - o Participants to speak to the group generally
    - o Switch off or silence mobile phones if possible
    - o Participants are free to ask for clarifications from the interviewer
    - o Keep confidential the interview discussion

Interview Guide

Where do you currently source web-based parent-to-parent support?

Which websites do you find currently provide parent-to-parent support?

What supports do you look for when you use the current sites?

How easy or difficult is it to find online parent-to-parent support?

What supports do you look for when you use the current sites?

How do these sites fulfil or not what you are looking for?

What are the strengths of these sites?

What are the gaps in these sites?

What do you think are the features an Irish website should provide?

What information should the site provide?

What support should the site provide?

What is the single most important 1?

What is the single most important thing that a parent-to-parent support site should provide?

Is there anything that we have not discussed that you would like to discuss?

Any other comments?

Recap for participants verification by research note taker of topics covered in interview.

Any comments?

Thank you for taking part and giving your time to the study.

Appendix 9: RD-WEB P2PS: Parent-to-Parent Support Telephone Format and Interview Guide

TELEPHONE INTERVIEW DETAILS	
Name of Interviewer (please print):	Interview Code Number: TI0
Date of interview:	Time of interview:
Participant's name:	Participant's phone number:
Participant's email address:	€40 (yes) / (no) Postal address:
Consent given (yes) / (no)	Interview recorded: (yes) / (no)

Opening	Hello, may I speak with ……. please
	Many thanks for agreeing to participate **in this RARE CONDITIONS IRISH WEBSITE – PARENT-to-PARENT study.**
	Are you free to take this call for the 15/20 interview? *If no: what time would suit you better?*
	Have you had an opportunity to read the information leaflet and the consent form?
	Have you any questions or queries about them you would like me to answer?
	Confirm participant's consent to participate.
	The study has ethical approval from Trinity College. It is a Trinity College and Saoirse Foundation partnership funded by the Irish Research Council.
	Today's interview will cover some of your demographic details, parent-to-parent support, web-based parent-to-parent support and what a future web-based parent-to-parent support should provide and any other comments you may like to make.
	Shall we start: Biographical Details
	There is a payment of €40 towards expenses you may have incurred in participating in the interview. The Saoirse Foundation will post the payment directly to you. Address?

Background	As you know the interviews are taking place as a result of recommendations made by the parents who took part in *'Web Information for Families of Children with Rare Conditions'* study for a parent-to-parent support feature in the proposed Irish rare condition website for parents involved in the care of children with rare conditions.
	And so the purpose of this interview to explore your views on parent-to-parent support and make recommendations (what the site might offer) to assist in the development of the parent-to-parent support feature in the proposed new Irish website.

Consent: *Ethics* *Confidentiality* *Recording* *Duration* *€40 payment*	**Confirm the participant received the consent form and has had time to read it.**
	Participation is voluntary. You can withdraw from the interview at anytime without any repercussions.
	With your permission the interview will be audio recorded this is to assist us with information collection and for our accuracy purposes.
	Our conversation today is being kept confidential.
	Your identity will not be revealed in anyway. Your name will remain anonymous (a code is used) in all published information emanating from the study. Your answers will be combined with those from other participants.
	All interview data are for research purposes only.
	All recordings are stored in secure password protected computers, to which only the researchers have access.

Questions	Prompts	Replies
Q1. **Opening Participants views on parent-to-parent support as a parent of a child with a rare condition**	**Have you any experience of being involved in parent-to-parent support?** What are your views on it? How would describe your experience of parent-to-parent support? How helpful did/do (not) find parent-to-parent support? What worked? What didn't work?	
Q2. **Participant's Current Online Parent-to-Parent Support**	**Currently** for web-based parent-to-parent support where do you search? (Facebook) Are there any particular websites you find provide parent-to-parent support? What supports do you find on these current websites? Are they what you are looking for? For you how easy or difficult have you found, finding online parent-to-parent support?	
Q3. **Participants views on what proposed**	**On the Future** the proposed new Irish website for parents of children with rare conditions.	What for you is the **ONE** most important thing the parent-to-parent support feature should have?

Parent-to-Parent Support feature should provide	What types of things should the parent-to-parent support feature provide? • What types of supports do you think the feature should provide? • What kind of support information should the feature provide? • In your opinion are there examples of good sites that we might visit?	

Question 4: Is there anything we have not covered that you like to discuss in relation to the development of parent-to-parent support?

Question 5: Is there anyone else who you think we should telephone?

If 'yes' record name, role, contact details below:
Recommended name:
Contact details:

€40 payment from Saoirse Foundation? *Yes/No*

Postal Address:

• Many thanks for your time and for taking my call.
• Just to let you know that the results from this study will be available on the Saoirse Foundation website.
• All the best and thanks again.

Any post interview comments or observations:

Would participant like me to follow up on this? Yes/No

Appendix 10: Sites Assessed by Participants

Organisation	Website Accessed	Site has Facebook Page
The Autism Society (USA)	www.autism-society.org	yes
Australian Mitochondrial Disease Foundation **AMDF**	www.amdf.org.au/	Yes
Bubble Foundation	www.bubblefoundation.org.uk	yes
Chromosome Disorder Outreach **CDO (US**)	www.chromosomedisorder.org	yes
Contact a Family	www.cafamily.org.uk	yes
Cleft Lip and Palate Association Ireland **CLAPAI**	www.cldft.ie	yes
Climb	www.climb.org.uk	yes
DCA Warriors FB page is designed to share information relating to domiciliary care allowances		www.facebook.com/galwayautismpartnership/.../4654118401571
Encephalitis Global Inc.	www.encephalitisglobal.org	yes
Epilepsy Ireland	www.epilepsy.ie	yes
Genetic and Rare Disorders Organisation **GRDO**	www.grdo.ie	yes
Mitochondrial Disease Action Committee **Mito Action**	www.mitoaction.org	yes

Rare Connect	www.rareconnect.org	yes
Special Needs Parent Association **SNPA**	www.specialneedsparents.ie	yes
Syndromes Without A Name **SWAN**	www.undiagnosed.org.uk	yes
Rare Chromosome Disorders Ire Facebook (Irish information only)		www.facebook.com/pages/Rare-Chromosome-Disorders-Ireland/...
The United Mitochondrial Disease Foundation **United Mico**	www.umdf.org	yes
Unique (Rare chromosome disorder support group)	www.rarechromo.org.html/home/asp	yes