

# Attitudes About Internet Support Groups Among Adolescents and Young Adults with Neurofibromatosis Type 1 and their Parents

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**Abstract** Youth with neurofibromatosis type 1 (NF1) have multiple, complex symptoms associated with physical, social-emotional, and cognitive difficulties. In addition, caring for a child with NF1 can be extremely challenging for parents. Since research with other chronic illness populations suggests that social support, including internet support groups (ISGs), can be beneficial, this survey study aimed to determine the attitudes and preferences of adolescents and young adults with NF1 and parents of a child with NF1 regarding ISGs. Thirty patients and 30 caregivers completed a 24-item survey about ISGs. Many patients and parents are not aware of any ISGs for NF1, but are interested in using one in the future for a variety of reasons, including to get answers to their questions about NF1, to find out about research studies, and to discuss problems and concerns about NF1. Specific concerns of interest include physical, social-emotional, and cognitive aspects of NF1. ISGs have potential as a social support intervention within the NF1 community. ISGs for the NF1 population should include patients with NF1 (or parents of children with NF1) as well as a health professional, and both chat rooms and discussion boards likely would be well-received.

**Keywords** Neurofibromatosis Type 1 · internet support groups · survey · social support · youth · parents

Neurofibromatosis type 1 (NF1) is a rare, autosomal dominant condition caused by mutations on chromosome 17. About half of all cases are spontaneous mutations (Tonsgard 2006). Symptoms and complications include plexiform neurofibromas (PNs), café au lait macules, optic pathway gliomas, Lisch nodules, and scoliosis, as well as cognitive deficits and learning disabilities (Hyman et al. 2006; Tonsgard 2006). Moreover, PNs can be disfiguring, often cause significant pain (Kim et al. 2009), and negatively impact quality of life (QOL; Wolkenstein et al. 2009).

With respect to social-emotional functioning, substantial percentages of patients fall in the at-risk and clinically significant ranges (Martin et al. 2012; Reiter-Purtill et al. 2008). Particular problem areas include depression and social withdrawal (Martin et al. 2012). Research further suggests that social problems in youth with NF1 are more severe in the presence of a comorbid cognitive disorder, such as a learning disability or Attention Deficit Hyperactivity Disorder (ADHD; Barton and North 2004).

The difficulties experienced by youth with NF1 also can pose numerous challenges to the parents who care for these children. Research from various patient groups suggests that caregivers of chronically ill youth are at risk for depression, anxiety, and loneliness (Florian and Krulik 1991; Kreutzer et al. 2009; Wood et al. 2008). Moreover, parents of ill children experience stressors in relation to their daily activities, social and family role disruption, and the child's treatment (Palermo and Eccleston 2009). In one study that examined the well-being of parents of children with NF1, parents' psychological functioning was within normal limits based on a self-report questionnaire. However, perceptions of less social support were correlated with higher levels of distress in

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mothers of patients with NF1; further, greater neurological impairment in the child was associated with perceptions of less social support and greater distress by their mothers compared with mothers of children with less neurological impairment (Reiter-Purtill et al. 2008). Other aspects of psychological functioning of parents of children with NF1 have not been given adequate attention in the literature to date.

Benefits of social support for youth with chronic illness and their caregivers include better disease management and improved physical and mental health (Janicke et al. 2009; La Greca et al. 2002; Skinner et al. 2000; Wang et al. 2013). Moreover, people often prefer to obtain support from similar others, such as those with the same condition. For example, substantial percentages of parents of children with autism (59 %) and Down Syndrome (41 %) endorsed the need to discuss feelings about their child with parents with a child with the same genetic disorder (Siklos and Kerns 2006).

In recent years, researchers have sought to develop and deliver internet-based applications, including internet support groups (ISGs), that address a range of health-related informational and emotional needs (Beckjord et al. 2007; Escoffery et al. 2008; Zrebiec and Jacobson 2001). ISGs offer a means of connecting geographically diverse individuals with similar challenges in order to provide support and understanding. The goal of ISGs is to facilitate positive changes such as improved self-esteem and coping (Melling and Houguet-Pincham 2011).

ISGs have been shown to be helpful in patients with a variety of conditions, including cancer (Winzelberg et al. 2003), diabetes (Merkel and Wright 2012), HIV (Mo and Coulson 2013), and Huntington's disease (Coulson et al. 2007). However, we found no published reports on ISGs for individuals with NF1. Moreover, a critical first step in designing and assessing interventions involves establishing the needs of the patients and families (Wen and Gustafson 2004). Research suggests that, while social support is a frequently reported need among patients with genetic disorders and their families (Kang et al. 2010), specific support-related needs can differ among disorders (Siklos and Kerns 2006). Thus, the aim of this survey study was to determine the attitudes and needs of youth with NF1 and their caregivers regarding the use of ISGs.

## Method

### Participants

Eligible participants for the patient survey included adolescents and young adults ages 12 to 25 years with NF1 who were enrolled on a NF1 natural history or treatment protocol at a government research institute. Most of the patients on this study had one or more plexiform neurofibroma tumors.

Eligible parent respondents had to be the primary caregiver of a child with NF1 who was participating in a study at the institute. The target enrollment was 30 patients and 30 parents.

### Instrumentation and Procedures

The patient and parent surveys, developed by members of our institution's Neurobehavioral Group and NF1 medical research team, each contained 24 items and took 10 min or less to complete. The items asked about past use of ISGs, current sources of emotional support, barriers to ISG use, the likelihood of using an ISG in the future, and preferences for ISG format and topics. Items were in multiple choice (15 items), 4-point Likert-scale (6 items), and open-ended format (3 items). For many of the multiple-choice questions, respondents were able to choose "other" and write in their own response as appropriate. The initial version was piloted with two patients and two parents, and minor modifications were made based on their input. The final version of the patient survey is displayed in the Appendix. Because the survey was anonymous, the Office of Human Subjects Research approved the project and determined it was exempt from review by the Institutional Review Board. A research assistant or member of the NF1 medical team administered the final surveys during a routine outpatient clinic visit.

### Data Analysis

Descriptive statistics were computed on the survey variables. Data were analyzed using SAS statistical software Version 8 (SAS Institute, Cary, NC). Open-ended responses were reviewed by two co-authors for content and specific examples are given in the text, where appropriate.

## Results

Thirty-one patients and 32 parents were consecutively approached for participation; one patient and two parents declined to participate citing a lack of interest. Thus, 30 patients ages 12 to 25 years and 30 parents (not necessarily of the same 30 patients) completed the survey.

### Past ISG Use

Of the 30 patient respondents, two (7 %) reported using an ISG in the past year. Of those, one reported finding it "very helpful" and one found it "somewhat helpful." Reasons for using an ISG in the past included wanting to help others with NF1 ( $n=2$ ), wanting to talk to others about feelings they had related to NF1 ( $n=1$ ), wanting health information ( $n=1$ ), and wanting to talk about things not related to NF1 ( $n=1$ ). Open-ended responses regarding what was helpful about the ISG

included “having a lot of people to answer a question” and “[talking] about where the tumors grow.”

Of the 30 parent respondents, nine (30 %) reported using an ISG in the past year. Of these nine parents, one found it “very helpful,” three found it “somewhat helpful,” and five found it “a little helpful.” Reasons for doing so included wanting medical information about NF1 ( $n=6$ ), to get emotional support related to their child having NF1 ( $n=4$ ), and to support others ( $n=3$ ). Similarly, responses to an open-ended question that asked parents what was helpful about the ISG, indicated both informational and emotional reasons, including “I got names of doctors and made friends” and “Generally knowing we are not alone.”

### Current Sources of Support

Patients were asked who they typically talk to about any feelings or worries they had related to their NF1. Responses included: parents (50 %,  $n=15$ ), physicians (30 %,  $n=9$ ), and therapists (7 %,  $n=2$ ). While about one third ( $n=11$ ) of patients reported talking to a friend who does not have NF1, only one patient (3 %) reported talking to a friend with NF1. Seventeen percent ( $n=5$ ) of patients stated that they do not talk to anyone about worries or feelings related to their NF1.

Among parents, the most common sources of emotional support regarding their child’s NF1 were family members (73 %,  $n=22$ ) and spouses (63 %,  $n=19$ ). Less commonly, they reported being supported by physicians (33 %,  $n=11$ ) and therapists (7 %,  $n=2$ ). Sixty-seven percent ( $n=20$ ) noted getting support from a friend without a child with NF1, while only 13 % ( $n=4$ ) said they were supported by a friend with a child with NF1.

### Barriers to ISG Use

On a multiple-choice item, the most commonly endorsed reason for patients not using an ISG currently was *not knowing of any* (69 %,  $n=21$ ). A few patients reported not knowing how to join one (10 %,  $n=3$ ), not wanting to communicate with people they did not know (14 %,  $n=4$ ), thinking it would not be helpful (7 %,  $n=2$ ), preferring to obtain support through other people or places (7 %,  $n=2$ ), or not having access to a computer (3 %,  $n=1$ ). No patients reported that their parent(s) would not allow them to use an ISG. On these items, respondents could endorse more than one option so the total is greater than 100 %.

The most frequent reasons parents cited for not using an ISG currently included not knowing of any (58 %,  $n=12$ ), feeling they would rather receive support from other sources (19 %,  $n=4$ ), and feeling that the information they encountered or hearing about other people’s problems would be overwhelming or depressing (14 %,  $n=3$ ). Other reasons were related to not wanting to talk to others about their problems (12 %,  $n=3$ ) and not knowing how to join an ISG (8 %,  $n=2$ ).

### Future ISG Use

When patients were asked how likely they would be to use an ISG in the future, nearly half (48 %,  $n=14$ ) indicated they would be “likely” or “very likely” to use an ISG to connect with others with NF1; fewer wanted to connect with others with any chronic illness (31 %,  $n=9$ ). Additional reasons included to get answers to questions about NF1 (45 %,  $n=13$ ), to find out about research studies (34 %,  $n=10$ ), and to talk about problems or worries (31 %,  $n=9$ ). It should be noted that one patient did not answer this question, and so percentages are out of 29 rather than 30 patients.

Parents reported being “likely” or “very likely” to use an ISG to find out about research studies (87 %,  $n=26$ ), to talk to other parents of children with NF1 (67 %,  $n=20$ ), and to get answers to their questions about NF1 (50 %,  $n=15$ ).

### ISG Preferences

When asked about their preferences regarding ISG format, the majority of patients indicated interest in a chat room that would allow them to “talk” to other patients with NF1 in real time, i.e., in a scheduled chat session (73 %,  $n=22$ ). Fifty-four percent reported interest in a discussion board where they could post messages at any time for other patients with NF1, and slightly fewer respondents noted a preference for a chat room (50 %,  $n=15$ ) or discussion board (50 %,  $n=15$ ) where they could communicate with a health professional. Moreover, 81 % ( $n=24$ ) reported that they would prefer an ISG that was available only to others with NF1, while 19 % ( $n=6$ ) would be open to an ISG accessible to patients with any chronic illness.

Parents indicated interest in a discussion board (67 %,  $n=20$ ) or chat room (53 %,  $n=16$ ) to communicate with other parents of children with NF1. Similar interest was garnered for a discussion board (67 %,  $n=20$ ) or chat room (53 %,  $n=16$ ) for communicating with a health professional. In addition, parents strongly preferred an ISG open only to parents of children with NF1 (90 %,  $n=27$ ) as opposed to an ISG open to parents of children with any chronic illness (10 %,  $n=3$ ).

### ISG Topics

Topics that patients expressed interest in communicating about via an ISG included treatment studies (80 %,  $n=24$ ), physical effects of NF1 (70 %,  $n=21$ ), social-emotional topics (e.g., depression, stress; 40 %,  $n=12$ ), and cognitive/academic problems (33 %,  $n=10$ ). Topics of interest among parents included treatment studies (90 %,  $n=27$ ), physical effects of NF1 (73 %,  $n=22$ ), social-emotional topics (60 %,  $n=18$ ), and cognitive/academic problems (57 %,  $n=17$ ).

## Discussion

To our knowledge, this is the first exploration of attitudes and needs regarding ISGs within the NF1 population. To date, no social support intervention studies have been published that address the challenges faced by patients and parents of children with NF1, although social support has demonstrated associations with positive outcomes in other chronic conditions (Hoekstra-Weebers et al. 2001; Monaghan et al. 2011; Rearick et al. 2011). Internet support groups may offer a unique opportunity to connect geographically separated individuals with NF1 and their families. Indeed, while approximately one-third and two-thirds of patients and parents, respectively, reported receiving emotional support regarding the child's NF1 from friends, only 3 % of children and 13 % of parents received such support from a friend with NF1 or a friend with a child with NF1, respectively. Comments from participants suggest that this was largely because they did not know any other families with a child with NF1.

Among our sample of youth with NF1 and parents of a child with NF1, past or current use of ISGs was rare. The primary reason for not using an ISG was not knowing of any. However, the majority of patients and parents reported being interested in utilizing such a group in the future for a variety of reasons, including getting answers to questions about NF1, discussing problems, and finding out about research studies. Topics of interest were treatment studies, as well as the physical, social-emotional, and cognitive effects of NF1. These topics parallel prior reports in the literature describing the common symptoms and challenges related to NF1 (Martin et al. 2012; Tongsgard 2006). Future investigations could examine relationships between ISG use and demographic factors (e.g., age, gender) as well.

## Practice Implications

Although several internet sites exist where individuals with NF1 and their family members can communicate with each other, a considerable percentage of patients and parents in our sample were not aware of any. Practitioners are encouraged to help patients and family members find an ISG that is appropriate to their needs. Given the preferences noted by our sample, ISGs for the NF1 population should include opportunities for communication with other patients (or parents) as well as a health professional. Thus, opportunities exist for professionals such as genetic counselors, therapists, and nurses to volunteer their time and expertise with an ISG. Interest among respondents in both chat rooms and discussion boards are indicated, as well as a preference for ISGs that are open to the NF1 community, rather than to individuals with any chronic condition.

## Study Limitations and Research Recommendations

Our relatively small sample size limits generalizability of our findings. In addition, most of the patients at our clinic have plexiform tumors, and thus our sample's responses may not be representative of the NF1 population as a whole. However, given the rarity of NF1, results can be considered as providing preliminary support for ISGs as a potential intervention. In addition, while we found that patients and parents of children with NF1 reported that they would be amenable to participating in an ISG, we cannot speculate about whether they actually would engage in one, nor can we know the impact that participation would have on emotional well-being or quality of life. Future longitudinal intervention studies are needed in that regard, with consideration of factors associated with attitudes and barriers to ISG use. Optimally, randomized trials comparing an ISG to a control group would allow for conclusions as to the effectiveness of the intervention. Mediating factors or subgroups that benefit differentially from the ISG should be considered. Our group currently is developing a pilot study to assess the preliminary effectiveness of an ISG in the NF1 population, with the methodology guided by our survey results.

## Conclusions

ISGs have the potential for offering a much-needed source of social support for youth with NF1 and their parents. Based on numerous outcome studies from other disease groups, it is reasonable to hypothesize that ISGs targeting the NF1 community would be beneficial. Our findings have implications for designing and implementing ISGs for youth with NF1 and their parents. Future studies are needed to target the social-emotional needs of youth with NF1 and their families through internet-delivered interventions.

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All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

**Conflict of Interest** Dr. Martin received funding for a trip from the Children's Tumor Foundation, and is co-Principal Investigator on a grant from the Neurofibromatosis Therapeutic Acceleration Program.

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Ms. Baldwin, Ms. Roderick, Ms. Tamula, and Ms. Gillespie do not have any conflicts of interest.

Dr. Widemann is a member of the scientific advisory board of the Neurofibromatosis Therapeutic Acceleration Program; she is a member of the editorial board of *The Oncologist* and an associate editor of *Frontiers in Pediatric Oncology*.

## Appendix

### Patient Questionnaire

1. When was the last time you used an ISG (internet support group)?

- ☐ Never – skip to question 7.
- ☐ Over a year ago – skip to question 7.
- ☐ Within the last year
- ☐ Within the last month
- ☐ Within the last week

2. In the past 12 months, how often did you use an ISG?

- ☐ Not at all – (go to question 7)
- ☐ Once
- ☐ Every few months
- ☐ Once a month
- ☐ Once a week or more

3. How many different ISG's did you use in the past 12 months?

- ☐ One
- ☐ Two
- ☐ More than two

Please list all ISGs you have used: \_\_\_\_\_

4. Thinking about the ISG you used most often in the past 12 months:

How helpful was it?

- ☐ Not at all helpful – go to question 6
- ☐ A little helpful
- ☐ Somewhat helpful
- ☐ Very helpful

5. What was helpful about the ISG? \_\_\_\_\_

\_\_\_\_\_

6. What was not helpful about the ISG? \_\_\_\_\_

\_\_\_\_\_

7. Which of the following, if any, are the reasons you do not use an ISG now? (check all that apply)

- ☐ I don't want to talk to others about NF1
- ☐ I don't know of any



- ☐ It costs too much (e.g., for internet access)
  - ☐ I don't have access to a computer
  - ☐ I don't know how to join one
  - ☐ My parents won't/wouldn't let me
  - ☐ I don't think it would be helpful
  - ☐ I would rather talk to other people about NF1
  - ☐ I don't want to "talk" to people I don't know on the computer
  - ☐ Other:
- 

8. If you have used an ISG in the past 12 months, what are the reasons you had for doing so? (check all that apply)

- ☐ To talk to others about my feelings or other things related to NF1
- ☐ To talk to others about my feelings or other things not related to NF1
- ☐ To reach out to and help others with NF1
- ☐ To get health or medical information for yourself
- ☐ To get health or medical information for someone else

9. In the past 12 months, who have you talked to about any worries or feelings you have had (check all that apply)?

- |  |  |
|--|--|
| <input type="checkbox"/> Parents                               | <input type="checkbox"/> Therapist/counselor/psychologist  |
| <input type="checkbox"/> Other family members                  | <input type="checkbox"/> Doctor                            |
| <input type="checkbox"/> A friend who <u>does not</u> have NF1 | <input type="checkbox"/> Other members of the medical team |
| <input type="checkbox"/> A friend who <u>does</u> have NF1     | <input type="checkbox"/> In-person support group           |
| <input type="checkbox"/> Teachers                              | <input type="checkbox"/> No one                            |
| <input type="checkbox"/> Other:                                |  |
- 

10. In the past 12 months, who have you talked to about any worries or feelings you have had about your NF1 (check all that apply)?

- |  |  |
|--|--|
| <input type="checkbox"/> Parents                               | <input type="checkbox"/> Therapist/counselor/psychologist  |
| <input type="checkbox"/> Other family members                  | <input type="checkbox"/> Doctor                            |
| <input type="checkbox"/> A friend who <u>does not</u> have NF1 | <input type="checkbox"/> Other members of the medical team |
| <input type="checkbox"/> A friend who <u>does</u> have NF1     | <input type="checkbox"/> In-person support group           |
| <input type="checkbox"/> Teachers                              | <input type="checkbox"/> No one                            |
| <input type="checkbox"/> Other:                                |  |
- 

11. If you have a question about NF1, where do you go to get information? (check all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> Parents                               | <input type="checkbox"/> Doctor                            |
| <input type="checkbox"/> Other family members                  | <input type="checkbox"/> Other members of the medical team |
| <input type="checkbox"/> A friend who <u>does not</u> have NF1 | <input type="checkbox"/> In-person support group           |
| <input type="checkbox"/> A friend who <u>does</u> have NF1     | <input type="checkbox"/> A website/the internet            |
| <input type="checkbox"/> Teachers                              | <input type="checkbox"/> Books or articles                 |
| <input type="checkbox"/> Therapist/counselor/psychologist      | <input type="checkbox"/> Other:                            |
-

12. In the past 12 months, how often have you used email or a social network (like Facebook) to “talk” to other people with NF1?

- ☐ Not at all
- ☐ Once
- ☐ Every few months
- ☐ Once a month
- ☐ Once a week or more

13. If an ISG were available, how likely is it that you would use it for the following reasons:

To connect with other people with NF1

- |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not at all               | Somewhat                 |                          | Very                     |
| Likely                   | Likely                   | Likely                   | Likely                   |

To connect with other people who have any kind of chronic illness

- |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not at all               | Somewhat                 |                          | Very                     |
| Likely                   | Likely                   | Likely                   | Likely                   |

To talk to others about problems or worries

- |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not at all               | Somewhat                 |                          | Very                     |
| Likely                   | Likely                   | Likely                   | Likely                   |

To get answers to my questions about NF1 from others with NF1

- |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not at all               | Somewhat                 |                          | Very                     |
| Likely                   | Likely                   | Likely                   | Likely                   |

To find out about research studies for children with NF1

- |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not at all               | Somewhat                 |                          | Very                     |
| Likely                   | Likely                   | Likely                   | Likely                   |

14. If you were going to use an ISG, which of the following format(s) would you be interested in? (check all that apply)

- ☐ Chat room where you could talk to others with NF1 who are on the website at the same time as you are
- ☐ Chat room where you could talk to a health professional who is on the website at the same time as you are
- ☐ Discussion board where you could post messages that others with NF1 could respond to at a later time
- ☐ Discussion board where you could post messages that a health professional could respond to at a later time

15. If you were going to use an ISG, which of the following topic(s) would you be interested in discussing with other ISG users? (check all that apply)

- ☐ Physical effects of NF1 – plexiform neurofibromas (tumors), skin bumps
- ☐ Learning problems, schoolwork, homework, special services
- ☐ Social/Emotional topics – sadness, stress, making friends, dating, loneliness
- ☐ Treatment studies for NF1
- ☐ Things not related to NF1
- ☐ Other: \_\_\_\_\_

16. If you were going to use an ISG, do you think it would be better to have:

- ☐ A group for people your age with NF1
- ☐ A group for people your age with any chronic illness (like cancer, diabetes, or asthma)

17. Is there a computer in your home?

- ☐ Yes
- ☐ No – skip to question 19.

18. If yes, are you able to use it as often as you like?

- ☐ Yes
- ☐ No

19. Do you have access to another computer outside your home (like at school or the library)?

- ☐ Yes
- ☐ No

20. How often do you use a computer (at home or somewhere else)?

- |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Less than<br>once a week | 1 – 2 times<br>a week    | 3 – 5 times<br>a week    | Every day                |

21. Are there certain times of the day that are best for you to use an ISG?

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