



## Resource Article

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"Supporting Families  
Through the Diagnosis Process -  
Looking Closer at Rare Conditions"

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Uncertainty can loom while parents seek answers for a child's undiagnosed condition. It can be the instigation of their personal search to gain a better understanding of a rare condition. Most parents at some point turn to the internet. They look for definitions of rare conditions, explanations of associated behaviors, information about treatment and prognosis, and connections with other parents with similar experiences. The Pew Internet Research Institute suggests that 80% of Americans use the internet to search for medical/health information. Given this trend of online research, it behooves us to get a better understanding how the internet can potentially help our families.

Oprescu, Campo, Lowe, Andsager, and Morcuende conducted a study examining how parents exchanged online information regarding clubfoot (2013). Clubfoot is a congenital abnormality affecting the lower limbs, occurring in approximately 1 per 1000 live births (Pubmed.gov, 2009). Although this condition may be apparent at birth with a diagnosis soon after, parents are often left feeling unsure about their treatment

options, as well as how this condition will generally affect their child's life. The authors used the work of Dale Brashers to understand *uncertainty* and how this concept motivates parents as they seek information, in the case of families with a child with clubfoot. Brashers defined uncertainty as a psychological state characterized by insecurity and lack of clear information (Communication and Uncertainty Management, 2001).

The authors selected the oldest and largest Yahoo-based, user-managed online support community dedicated to clubfoot to sample their user messages. This online community had more than 76,000 messages exchanged over a 10-year period. It has more than 2300 members with 20 new members joining each week and provides informational and social supports for its users. The authors randomly selected messages (1 in every 100 postings) over a 10-year period from the time the group formed in January 2000 to December 2008. A total of 775 messages were selected and analyzed. Messages were coded using Brashers information-seeking schema: (1) question-asking, (2) self-disclosure, (3) offering a candidate answer,

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(4) second-guessing and (5) passive information seeking.

Results revealed that women posted more than men (86% versus 6%, respectively; gender unknown 8%). Most messages (80%) were replies to a previous message. Twenty percent of messages were initial messages suggesting an average of 4 responses for each message posted. Most of the messages (73%) were directed toward an individual, whereas, fewer (27%) were intended for the online community as a whole. In terms of Brashers information seeking behavior theory, direct questioning (25.3%) was most common, followed by self-disclosure (15%), and relatively less common were offering a candidate answer and passive information seeking (both at 4%) and lastly second guessing was most uncommon at less than 1% (0.4%). About one third (33%) of 775 responses provided information, such as names of health care professionals or institutions. Of those responses that provided additional detailed information about providers/institutions, 54% were positive and 36% of the messages strongly suggested getting a second opinion. Messages regarding detailed medical information consisted of 13% of the 775 messages. The most common of those addressed bracing (45%), followed by providing general information about clubfoot and treatment options (13%), 11% addressed relapses, 11% addressed casting issues. More than half of the postings (60%) were based on personal experience, 20% were posted by medical professionals and 5% were references to medical textbooks/journals or hospital websites. The authors also noted that information-seeking messages were, "...generative, dynamic, multilayered, and repetitive" and "...most information seeking

messages seem to originate from new mothers who recently joined the community following a diagnosis..." (Oprescu, et al., 2013, "Results," para.5).

Members of this online community appeared to manage their uncertainty by seeking information and sharing experiences (self-disclosure). When you consider the responsiveness of this online resource (4 responses for each new message) parents were tapping into a connection with others that is difficult to achieve through traditional medical outlets. It appears through this forum, parents were able to build trust, gain confidence, and ultimately help manage their uncertainty.

There are certainly caveats to seeking information on the internet. Not all sources are reliable and research based. Some online communities are not as interactive and up-to-date as others and some are simply not helpful because their information is poor. However, online communities can offer timely, interactive and personal perspectives that rarely happen in a medical setting. Ideally, professionals working with families to diagnose rare conditions can provide parents with websites that offer up-to-date research based information about those disorders, as well as online support communities for the families.

Oprescu, F., Campo, S., Lowe, J., Andsager, J. & Morcuende, J. (2013). Online Information Exchanges for Parents of Children with a Rare Health Condition: Key findings from an online support community. *Journal of Medical Internet Research*, 15 (1):e16. doi:10.2196/jmir.2423



# What do the data say?

## How can I trust the information I find on the internet related to rare conditions?

Just because you read it on the web does not mean that it is credible. We know that nearly every opinion and perspective can be posted online. We also know that the internet is a great source for information, provided it is up to date, correct, and from a reliable source. But how can one know if the information being accessed is dependable? When it comes to information about rare conditions the Access To Credible Genetics Resource Network created a useful tool called “Trust It or Trash It?”. Included here is a handy version of the tool that is also available online at [www.trustortrash.org](http://www.trustortrash.org)

## Trust It or Trash It?

**How to use the *Trust It or Trash It?* tool**

Use this tool to help you think critically about the quality of health information found on websites, handouts, booklets, and more.

Consider three questions to guide you through the critical thinking process:

- (1) *Who said it?*
- (2) *When did they say it?*
- (3) *How did they know?*

**Who said it?**

*Who wrote the information you are reading?*

- ✓ **Think about TRUSTING IT if:**
  - The author’s name is easy to find.
  - The authors have experience with the condition and are respected in the community and by their colleagues.
- ✗ **Think about TRASHING IT if:**
  - You don’t know who wrote it or you can’t find the author’s name.
  - You can’t find information about the author’s background or experience, or you can tell they don’t have any experience.

*Who provided the facts? Where did the facts come from?*

- ✓ **Think about TRUSTING IT if:**
  - You can tell where the information comes from – the sources are listed.
- ✗ **Think about TRASHING IT if:**
  - You can’t tell where the information comes from – the sources aren’t listed.

*Who paid for it?*

- ✓ **Think about TRUSTING IT if:**
  - The sponsor has a lot of experience with the condition and the information doesn’t try to sell a product or point of view.
- ✗ **Think about TRASHING IT if:**
  - The sources listed for the information aren’t clearly related to the content or appear to be selling something.
  - Information about the funding or sponsoring group isn’t provided.

## What do the data say? *(continued)*

### When did they say it?

*When was it written or updated?*



**Think about TRUSTING IT if:**

-The information is current.



**Think about TRASHING IT if:**

-The information seems out of date based on other information you've read about or know.

-A date for the information isn't given.

### How did they know?

*How do you know this information pertains to you?*



**Think about TRUSTING IT if:**

-The medical information is based on research on many people.



**Think about TRASHING IT if:**

-The information is based only on someone's opinion or individual experience.

*Does the information seem reasonable based on what you've read or know?*



**Think about TRUSTING IT if:**

-The information matches what you've found in multiple other sources.

-If there are no other sources with the same information, it could be new, cutting edge research. (See the second "Trash it" statement below).



**Think about TRASHING IT if:**

-The information presented is clearly wrong given the current state of the science and the opinions of many experts.

-If there are no other sources with the same information and it seems too good to be true, it may be. (See the second "Trust it" statement above).

### For more information

Contact us at [trustortrash@geneticalliance.org](mailto:trustortrash@geneticalliance.org) for questions, comments, or suggestions on the *Trust It or Trash It?* tool. An online version of the tool is available at [www.trustortrash.org](http://www.trustortrash.org).

This version of the *Trust It or Trash It?* tool is based on the content contained in a more comprehensive tool created for developers of quality educational materials, as part of the Access to Credible Genetics Resource Network (ATCG). To see the developer's tool, visit [www.developerstrustortrash.org](http://www.developerstrustortrash.org). To learn more about the ATCG project and partners, visit [www.geneticalliance.org/atcg](http://www.geneticalliance.org/atcg).

The online version of this resource also includes helpful interactive scales to consider the content, quality, and usability of information about rare conditions found online and is other resources, such as handouts. This tool is also recommended for those developing information.



## Consultation Corner

From September through December 2016 we are excited to have **Dr. Deborah A. Bruns** as our Consultation Corner expert. This series will explore *Supporting Families Through the Diagnosis Process and Looking Closer at Rare Conditions*.

Further understanding of rare diagnoses:  
Service providers do not know all

Parents and service providers must work together on behalf of children with rare diagnoses. Both bring expertise and, combined, offer a great deal of information and input to reach desired outcomes. Yet, there is also much that is unknown and there is new information being discovered. Decades of research and advances in science and technology have made it easier to understand contributing factors and treatment approaches of many diseases. Knowing the cause can, but does not always, ease identification of intervention options. In fact, many identified and rare diseases have known causes, but lack viable treatment approaches. Fortunately, other conditions have both known causes and worthwhile intervention possibilities. There are also the combinations of unknown origin with known and unknown viable treatment options. As service providers, we cannot know everything. Rather, we too must be lifelong learners. We cannot be well versed about the implementation of every specific strategy, we cannot know the benefits of all new forms of therapy,

or completely understand long-term outcomes for a child with a rare diagnosis.

Parents often want us to know it all, especially with a child with a rare diagnosis such as trisomy 18 (Edwards syndrome) or an encephalocele. But they too know this is not possible. Parents also want individuals who will listen to their questions and concerns and provide relevant resources. Parents look for people they can trust. We do not have to have all the answers, but being a good listener with a sympathetic ear is sometimes all that is needed or needed most at different moments. There is also power to saying "I don't know but I'll do my best to help you find out". Having the honesty to share what you know and do not know is key. It assists parents to see themselves as competent and able advocates for their child.

In my experience as a practitioner and lead researcher with the Tracking Rare Incidence Syndromes (TRIS) project (see <http://tris.siu.edu>), I have come into contact with many parents who know way more than I ever will about their child's unique needs. An outcome I've seen is when parents are listened to and

## Consultation Corner (continued)

respected for their knowledge; they become better advocates for their children. I have learned so much from the TRIS project parents, which has, in turn, improved the project to better meet parent needs. Especially for parents with a child with a rare diagnosis, negative interactions can often occur with medical professionals. This is not the rule but it happens frequently. Again, drawing on my experience as a researcher with the TRIS project, I have heard countless stories from parents of medical professionals offering pessimistic recommendations including reduction or cessation of treatment. They point to the literature to support their recommendations. While important, there is also the need to seek information from colleagues for example. Decisions should not be solely based on a study that may be out of date, based on a small sample, or have other limitations. Yet, there may be a tendency to point to the research as definitive. Looking to parents' experiences is not necessarily favored as it is thought to be subjective. How can it not be? The experience itself is still

informative whether the outcome of surgery, for example, is positive or negative. By contrast, I celebrate parent knowledge and communicate what I don't know. Parents have expansive knowledge of their child's daily and specialized care. They also live with their decisions while service providers come in and out of their lives.

Service providers should empower parents. Parents are their children's voice. There is no crystal ball for a child with a rare diagnosis. One child may walk independently, while another needs a gait trainer, and a third will always need someone to push his wheelchair. We need to discuss all the possibilities and then step back so parents can make informed decisions. We are not all knowing, we can't be. There is always something more to learn especially when a child has a diagnosis that is unique in regard to prevalence and our experience as a service provider. We need to look to parents to learn together and expand what is known about conditions such as trisomy 18 and encephalocele.

Tracking Rare Incidence Syndromes (TRIS) Project is designed to raise awareness and provide support for families and professionals involved in the care of children and adults with rare trisomy conditions. The project evolved from parents seeking more information about their children's rare trisomy conditions related to day to day and medical decision making. The project's audience includes family members, medical and educational professionals, as well as other stakeholders interested in raising awareness and making connections for the benefit of children and families touched by rare trisomy conditions.

Learn more about TRIS online and meet the staff, review case studies, view publications and presentations, explore resources, and learn about the TRIS Survey, which is designed to collect information about parent and child experiences over time.



## On the WWW

This month we share some RARE resources.

RARE is part of Global Genes, an advocacy group aimed to build awareness, educate others about rare diseases, connect stakeholders, and provide resources.

RARECast is a series of podcasts on various rare condition and factors unique rare diseases. The podcasts include topics related to treatment, research, advocacy, and family

stories. RARE Podcasts are available at: <https://globalgenes.org/rare-cast/>

RARE Webinars are also available on various topics, such as “Understanding Gene Therapy,” “Keys to Effectively Communicate with Health Care Providers,” and “How to Discuss Genetic Disease with Your Loved Ones.” The RARE webinars are online at <https://globalgenes.org/webinars/>



## Continuing Education for KIT Readers

The Comprehensive System of Personnel Development (CSPD) is offering a continuing education opportunity for KIT readers.

In line with the focus on *Supporting Families Through the Diagnosis Process—Looking Closer at Rare Conditions*, readers are invited to receive continuing education contact hours for reading the monthly KIT publications (September - December 2016) and completing a multiple-choice exam about the content covered in these KITs.

KIT readers will receive the exam in January 2017. There is no need to register for the CEUs. Rather, if you are interested complete the exam online at [www.edis.army.mil](http://www.edis.army.mil)

Upon successful completion of the exam, you will receive a certificate of non-discipline specific continuing education

KIT Newsletters  
are available  
online at  
[www.edis.army.mil](http://www.edis.army.mil)

Thank you for your continued interest in the KIT.

