



The International 22q11.2 Foundation Inc.

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Summary of 22q Community Survey Results

In October of 2015 the International 22q11.2 Foundation published an online survey as part an effort to better understand and meet the needs of the worldwide 22q community. Sadly, earlier in the year, two other national organizations for 22q closed. Understanding that the loss of these two organizations would have a significant impact of the flow of information to families, the International 22q11.2 Foundation prepared to adjust its priorities in order to address these changes within the 22 community. As part of our process, we created a 22q community survey.

The anonymous survey ran for approximately three months on the homepage of our website. There were 222 responses: Of those who responded:

- 87% identified themselves as a parent;
- 8% as another family member including 4 persons with the 22q deletion;
- 5% as someone from a different category (professional, friend, etc.).

We also asked those completing the survey to tell us the age of the child they were writing about.

The responses were:

- 52% age 0-11;
- 33% age 12-21;
- 15% age 22 or older.

The questions we posed were:

- How can we best meet your needs?
- What would make a difference in the day-to-day life of your family?
- What are your worries about and hopes for the future?
- What would you like 22q treatment and research professionals to know?

As one might expect, the answers were highly varied. But certain “themes” became obvious as we culled through the responses, and those themes will guide us for years to come as we implement strategies to improve awareness, diagnosis, research and treatment.

With 222 individual responses to the above four questions, there was simply no way to list all of the responses in a readable way. Therefore, after carefully reviewing all of the contributions, we have summarized and highlighted specific responses as follows:

- **How can we best meet your needs?**

The variety of answers was no surprise. However, one consistent theme was for the International 22q11.2 Foundation to provide information, information, and more information. Though stated in a

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variety of ways, it is clear that our traditional role of being a clearinghouse for the latest treatment and research news is important to most. However, just *passing along* information is not sufficient if that information hasn't been vetted by the appropriate experts, lacks specific context to help parents determine if the information is relevant to their situation, and is written in such a way as to be understandable and free of jargon.

One respondent stated:

“Create major public awareness. Be the connector of providing resources to local clinics/physicians and to local groups/families. Be a 'one stop shop' of information.”

Many asked for more information on transitions to adulthood and mental health issues, exemplified in these two comments:

“Updated medical findings, parent to parent support, specialist information, specific needs for adults with 22q, mental illness information”

“Educational meetings for us and materials I can provide to educators and others involved in my child's life. Specifics in dealing with transitions through puberty and beyond.”

Many of those who responded were anxious to have the Foundation take a leadership role in organizing parents, support groups, meetings Parent Support Group Meetings for families and caregivers including regular updates using social media:

“I feel the widespread impact the Dempster Foundation had within each state (Facebook pages, visits, etc.) is what we will miss the most. This is a need that has to be met in order to further educate the world about 22q DS.”

The Foundation's plans for 2016 include a series of inspirational and educational videos for families and professionals; in fact, scheduled filming is already under way.

- **What would make a difference in the day-to-day life of your family?**

While there was some overlap with the prior question, especially regarding transitions and mental health issues, in general those responding would like to see more awareness, more resources and more information concerning all aspects of 22q. Many of those responding zeroed in on their need for *practical* information that they can use immediately and also share with those who interact with their child on a regular basis. When The International 22q11.2 Foundation revamped its website (www.22q.org), one main goal was the accessibility and comprehensiveness of the information it contains. While work on the website continues - and always will, users should now be able to more easily find, and share, state-of-the-art information about all things 22q. In addition, we have a world renowned Medical Advisory Board that we tap into continuously to respond to family queries and concerns – keeping in mind that we cannot provide individual medical advice.

Support

“To have a support system (whether local or via the internet) that understands what we are going through and who can answer questions because they've been through these things before.”

“...more relief from the day to day struggles of relating to our daughter.”

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The Foundation has a growing, nationwide network of family support groups that bring families together and that provide information about local resources within their region, state or community. The Foundation's Facebook page and toll-free helpline are also key components of its efforts to ensure that no family feels alone with the diagnosis of 22q.

Education and Awareness

"More educational, recreational, and opportunities for our children and adults. More research and resources to gain knowledge about how best to overcome and or cope with the various anomalies. delays associated with 22q."

"...Awareness and knowledge of 22q11.2 amongst medical and school professionals in more rural areas. A better understanding of the syndrome in the medical and teaching professions would certainly enable physicians and teachers to think outside the box and provide the services these children require."

"Knowing the best resource potentials/avenues for helping with academic challenges/developmental delays/language processing/speech issues. Reading that the educational gap is just going to widen - instead of narrow or remain what it is as our daughter gets older is deflating. Are there things that can be done to alter this outcome? Successes in different methodologies with certain disabilities?"

The Foundation's website has detailed [information for parents, healthcare providers and other caregivers](#) vetted by 22q specialists, that covers all stages and areas of development, beginning at infancy, and including recently added content for teens and adults.

Our Same Name Campaign will soon see the addition of an infographic that will help better educate the 22q community of families and professionals about the diagnostic confusion resulting from multiple names for the same syndrome. The International 22q11.2 Foundation has been a leader in tackling this problem.

We are developing a series of webinars with 22q researchers and clinicians from around the world that address numerous high-interest topics identified in these survey results.

Transitions and Aging

"Knowing more about older age patients with 22q. We have an idea of the immediate issues we face, but not much understanding of how it all plays out beyond adolescence."

"Dealing with the uncertainty of independent living; trusts; guardian; durable power of attorney; disability benefits..."

Specific content at 22q.org addresses many issues associated with aging and its associated challenges including legal, financial and independent living. In addition, the [2016 summer conference](#) in Sirmione, Italy, which the International 22q11.2 Foundation is co-sponsoring, will have dedicated breakout sessions regarding transitions to adulthood.

From the inception of our Foundation we have tried to link families to summer camp programs such as Paul Newman's The Whole in the Wall Gang Kids and Dragonfly Forest. Moving forward we will

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continue to encourage existing programs to support those affected by 22q11.2 deletions and duplications and their families.

- **What are your worries about and hopes for the future?**

Most parents sometimes worry about their children's future. But parents of those with 22q worry endlessly. While no surprise to us, we heard that loud and clear in the responses provided. No organization can eliminate parental worry, but there is much we can do to provide hope. One key to that is our work to connect families with one another through our ground breaking Annual 22q at the Zoo Worldwide Awareness Day Event which touches thousands of parents, professionals and the lay public alike; through our official Facebook page; and through our Family Support Network. Parent to parent contact has been shown to be highly desirable by parents of children with any type of special need. Understanding how other parents have "traveled the 22q road" helps parents of younger children visualize what the future might look like and to take the necessary steps to ensure the best, possible outcome. Even parents of older children need to learn from one another, especially during the often challenging adolescent period and transition to adulthood.

Some of the more profound and moving responses were as follows:

"That he will use his syndrome as an excuse I worry that my son will not be able to function independently as an adult."

"I worry about struggles in school and the potential for mental health issues. I worry my child will be pigeon holed by teachers or picked on by kids who find out about the 22q. I'm hoping that school doesn't become too tough to handle and mental health stays good. I'm hoping for an independent and productive life for my child."

"I worry how my child will learn. I also worry about her heart defect."

"I worry about my two younger children with the duplication and what their futures hold specifically my child that has several mental health issues. I hope in the next couple years more research and info will be available."

"I'm worried about the possibility of schizophrenia."

"I hope that my son finds fulfillment and happiness in his life."

- **What would you like 22q treatment and research professionals to know?**

Fully engaging with doctors, therapists, counselors, educators and scientific researchers is essential if we are going to see improvements in our understanding of and treatment for 22q. Encouraging students and younger professionals to make 22q a focus of their careers is particularly important in ensuring future progress. The International 22q11.2 Foundation serves as a link between families and professionals, helping parents better understand the work of the professionals, and how to best engage with them, while also helping the professionals increase their understanding of the challenges that

families, including those with a 22q deletion or duplication, face every day. Here are some of the things you told us:

“That all of the information related to 22q needs to be up-to-date and easily accessible to everyone via internet.”

“That it can be very daunting to navigate all the different issues that go along with 22q and it would be nice to get support in coordinating everything.”

“It is very difficult to raise a child with 22q, especially with the mental health and behavioral issues often accompanying the health issues.”

“22q11 clinics should exist at every major children's hospital, as well as clinics that specialize in issues directly effecting those with 22q”

“There are direct correlations to the work that research professionals do for families. The more families can get educated by professionals and vice versa, the better the quality of life for those with the deletion.”

“It is terrifying at times to be the one responsible for thinking of/remembering/researching what types of things we need to be on the lookout for at different points along this journey. How often and when should certain things be tested? What fluctuates and what can be ruled out? We can be so focused on things like heart defects and monitoring those, that others may slip through the cracks. We have fears that we will miss something and that would be detrimental to our daughter. A "checklist" of sorts available to families would be AWESOME. Something to keep track and chart what needs to be monitored/rechecked as we navigate things.”

The Foundation provides a link to a [Medical Needs Checklist](#) for parents and caregivers of newly diagnosed children and we support The Biennial International 22q11.2 Professional and Family Meetings whose locations move around the globe every two years.

“That every case is unique and there is no telling what a person with 22q can do!”

“That my daughter has far exceeded what her expected abilities were predicted. With help she is living a productive life and never underestimate what these children can achieve. Don't ever give up on the research.”

“These kids are so complex that it is so hard for a family sometimes to figure out what is wrong. That being said, I would like them to be willing to listen and ask questions we are 22q experts [about] our own children.”

“Protocols for ongoing care for these individuals is crucial. The psychiatric care is crucial. Having access to the top researchers in the world is crucial.”

“There are sufferers out there who have absolutely no one to turn to. Education in and of its own is not enough. We're tired of hearing about education and awareness. It's time to actually DO something to give people some hope.”

“Parents have an astonishing amount of collective knowledge. One Facebook post/question can elicit hundreds of responses with valuable community-based research and anecdotal evidence. We worry about our kids past the age of 18 - the rest of the community should too.”

“Please don't give up seeking answers.”

The Foundation is sharing the survey results and, in particular, the answers to this final question, with its international body of Scientific & Clinical Advisors.

Conclusion and Next Steps

A survey, in and of itself, is only the beginning. Those of us at the International 22q11.2 Foundation realize that we have our work cut out for us. But reading the heartfelt, informative and passionate responses inspires us to work even harder. For that, we thank you. As we move forward, we promise to continue to listen and to communicate regularly. We will enhance our efforts to bring families and professionals together in meaningful ways. We won't be able to do it alone; we will need the entire 22q community to stay engaged and supportive. Responses to our survey raised many critical and profound questions and issues. With your help, we will tackle them one by one.

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