

## **FUNDRAISING ASSISTANCE:**

We are aware that there are costs that families incur when traveling to this event that could possibly impede their participation. In an effort to assist you, we have put together a list of Funding Agencies that offer grants to families to defer conference travel expenses.

Many community organizations are responsive to the needs of families wanting to attend conference. We urge families to seek financial support through your state ARC, local school systems, social service agencies, national/state disability programs, regional businesses, and/or service clubs, emphasizing the opportunity to learn from experts on 22q syndrome. Please note some Medical Spending Accounts will cover registration.

### **CROWDFUNDING TIPS FOR 2018 FAMILY CONFERENCE**

After researching several crowdfunding sites, we think the best option for 22q syndrome families who would like to raise money for 2018 Family Conference is to use YouCaring. Unlike other crowdfunding platforms (like GoFundMe), YouCaring does NOT have a fee. So in other words, you can raise money for your child without having to worry about a large percentage getting taken out at the end! (see more detailed tips below)

### **NATIONAL AGENCIES OR GROUPS**

**The ARC of the United States.** Each chapter offers different programs/services, so you need to check your local chapter: <http://www.thearc.org/find-a-chapter>. As an example, the ARC of IL offers a Consumer Stipend Project which offers grants to enable people with developmental disabilities and their family members to attend conferences of their choice that are directly related to developmental disability issues: <http://www.thearcofil.org/programs>.

**The Prayer Child Foundation**, based in Arizona, provides assistance to children that are 18 years and younger with physical and emotional challenges. They provide support to individuals located within the PCF's supporters' local communities, but it is not clear where those communities are. There are no other specific guidelines, and they have a very open application process with no application deadline. They promise a 6-week turnaround: [http://www.prayerchild.org/submit\\_request.html](http://www.prayerchild.org/submit_request.html).

### **STATE AND/OR REGIONALLY LIMITED**

All states have **Councils on Developmental Disabilities**, and some will fund conference travel. Some states require that you agree to share the knowledge

you gained at the conference with others groups in your state (and we would recommend that you target schools/classrooms with other students with DS as your point of sharing, as often there is not another family with DS nearby). We have tried to identify all the active programs across the United States, but if your state is not listed below, you should take a minute to review your own state's CDD page in case we have overlooked something. Click here for a roster of Developmental Disabilities Boards by state: <http://www.nasdds.org/state-agencies/> Click on your state and then on "county boards" and select your county of residence. **January is a key month, in that funds are typically appropriated at the beginning of the year on a first-come, first served basis.**

**For states that are not listed below,** if there was no specific link to a consumer investment/empowerment fund, it does not mean there is not such a fund in your state. Contact the council directly and inquire if they have available grants to help families & individuals with disabilities to attend conferences relating to that disability.

For families in **Florida, Indiana (including the greater Michiana area), Rhode Island and New York**, an organization called Hannah & Friends funds quality of life grants for families who care for children and adults with special needs. 2018 funding is opens in March: <http://www.hannahandfriends.org/resources/hannahs-helping-hands-grants/>

**Idaho:** The state's Council on Developmental Disabilities provides funding for families to attend conferences relating to a family member's disability. You need to file a post-attendance report stating outcomes/lessons learned and a plan to share what you've learned with other Idaho families affected by developmental disability. Deadlines are **30 days** prior to the conference: <http://www.icdd.idaho.gov/resources/funding.html>.

**Illinois:** Illinois StarNet has a Family Fellowship to reimburse parents for the expense of attending workshops, seminars, or conferences, up to \$200 annually: <http://www.thecenterweb.org/starnet/funding.html> They give preference to in-state events, but it would still be worth a shot. The deadline appears to be ongoing.

**Indiana:** The state's Consumer Investment Fund supports conference travel. The application is a bit challenging, but they will fund up to \$1000 per family to attend conferences relating to the family member's disability. Deadline is **5**

**weeks** prior to an out-of-state event: [http://www.in.gov/gpcpd/files/Individual\\_CIF\\_Application.pdf](http://www.in.gov/gpcpd/files/Individual_CIF_Application.pdf).

**Maryland:** The state's Developmental Disabilities Council supports travel to out-of-state conferences. There is no fixed amount, but they encourage cost-sharing with families, rather than subsidization of the entire costs. Deadline is a minimum of **90 days** prior to conference: <http://www.md-council.org/funding/conference-participation-fund/>.

**North Carolina:** The state's Jean Wolff-Rossi for Participant Involvement Fund offers up to \$800 per person (and up to a maximum of \$2400 per event, regardless of how many people apply) for participation in out-of-state conferences. Deadlines for application are **30 days** prior to an out-of-state event; decisions are made on an ongoing basis: <http://nccdd.org/initiatives/conference-funding/rossi-fund.html>.

**Ohio:** The Cuyahoga County Board of Developmental Disabilities Family Support Program may fund registration costs for conferences for families on topics related to the eligible individual. Prior approval is required for this program to fund training and conference attendance. The cost of these services will be deducted from your total annual program allowance. To check eligibility, email [familysupport@cuyahogaBDD.org](mailto:familysupport@cuyahogaBDD.org) or by phone at 216-241-8230.

**Oregon:** The Consumer Involvement Fund is available for residents of Oregon. You can find the application at: [http://ocdd.org/index.php/ocdd/docs/consumer\\_involvement\\_fund\\_application\\_for\\_individuals/](http://ocdd.org/index.php/ocdd/docs/consumer_involvement_fund_application_for_individuals/) or call 800-292-4154 to check availability.

**South Dakota:** The state's Council on Developmental Disabilities provides funding up to \$750 per person for out-of-state conference travel. Deadline is **60 days** prior to the event. Program details and the application can be found here: <https://www.state.sd.us/eforms/secure/eforms/E0512V2-DDCRequestTravelExpenses.pdf>.

**Tennessee:** The state's Council on Developmental Disabilities provides grants of up to \$500 for individuals, and \$1000 for families, to attend conferences related to a family member's disability. Deadline is **30 days** prior to the event: <http://www.tnstep.org/news/?id=460>.

## **MEDICAID/WAIVER PROGRAM ENROLLEES**

If your child is on Medicaid, especially a home and community based waiver, check with your case manager. Many waivers offer educational assistance for parents to attend conferences, paying the registration fee. Travel is not typically covered, but it is worth asking about.

## **OTHER POTENTIAL FUNDING SOURCES**

Funds may also be available through your church or synagogue; respite services, your local United Way, Kiwanis, Rotary or Lions Club.

## **PREPARING TO APPLY**

Some organizations may not have a form to fill out—in that case, you will need to write a letter or a personal statement and submit that. Here are some suggested guidelines for what to include in that letter (with thanks to FamilyConnect.org for the model). It may be that some of these are not relevant to you—they are meant only to serve as a guideline, not to be followed rigidly.

**A summary statement:** “I am asking for your financial assistance in providing travel and convention funding necessary so that I/my family may attend the International 22q11.2 Family Meeting in Whistler, Canada on July 14-15, 2018.”

**Introduce your child and explain 22q11.2 Deletion Syndrome:** “My child, \_\_\_\_\_, is \_\_\_\_\_ months/years old and has 22q11.2 deletion syndrome. The 22q11.2 deletion is a chromosomal difference, which is the result of a small piece of chromosome 22 not being present. The 22q11.2 deletion can result in a variety of problems, including but not limited to heart defects, immune system dysfunction, hypocalcemia, palate problems, feeding difficulties, kidney differences, difficulties in school, and learning disabilities. Individuals with a 22q11.2DS can expect the condition to last a lifetime. At this time, there is no cure for the deletion though treatment for the medical, academic and behavioral symptomatology is available. More specific details about the syndrome can be found at the International 22q11.2 Foundation website: <http://www.22q.org/>. [You should add a few details here about your child’s personality or the severity of the presentation of symptoms, etc., to help personalize the request.]”

**Introduce your child and explain 22q11.2 Duplication Syndrome:** “My child, \_\_\_\_\_, is \_\_\_\_\_ months/years old and has 22q11.2 duplication syndrome. The 22q11.2 Duplication is caused by an extra piece of genetic material on the 22 chromosome. The 22q11.2 duplication has the potential to affect many systems in the body and can cause a wide range of health problems. No two people are ever exactly alike, even when they have the same syndrome, and not every person with the duplication is affected in the same way. Though not always present, the key characteristics of this syndrome include combinations and varying degrees of; Heart defects, Palate differences, Feeding and gastrointestinal difficulties including reflux, Immune system defects, including neutropenia, Growth delays and short stature, Weak muscle tone or hypotonia, Hearing loss, Occasional endocrine issues including low calcium and thyroid differences, Cognitive, developmental and speech delays, Frequent upper respiratory infections, asthma, Behavioral and learning differences including ADHD, autism, Asperger Syndrome, etc., Seizure disorders, Macrocephaly or large head  
Individuals with a 22q11.2DS can expect the condition to last a lifetime. At this time, there is no cure for the duplication though treatment for the medical, academic and behavioral symptomatology is available. More specific details about the syndrome can be found at the International 22q11.2 Foundation website: <http://www.22q.org/>. [You should add a few details here about your child’s personality or the severity of the presentation of symptoms, etc., to help personalize the request.]”

**A statement of the costs:** How much will it cost (which you should probably work out before you write this section) and how much of the costs will you be able to come up with on your own.

**A statement of your goals in attending the conference:** “By attending the conference I hope to gain valuable information in order to enrich my family’s relationship with, and to provide the best possible support and care for, our child with 22q syndrome. The conference will also provide enormous family support as we make connections with other families affected by this rare, and sometimes isolating, disorder.” [You might also here indicate if your child has siblings who would be attending and if that would be a particular benefit.]

**Procedures of the conference:** “The International 22q11.2 Family Meeting will last two days, plus an additional Family Day. Sessions are geared toward coping skills of parents, educational and medical know-how in parenting our children, important updates from top scientific researchers in the field, as well as social activities for 22q11.2 children, their siblings, and parents.” You might also want to include the event agenda and/or list of confirmed speakers.

**A detailed budget:** “Our plane tickets will cost \$\_\_\_\_\_. Taxi fare from the airport (round trip) will be \$\_\_\_\_\_.” Or, “We will be driving our own vehicle \_\_\_\_\_ miles to the conference and back. Mileage expenses for the trip will be \_\_\_\_\_ . [here, use the IRS formula for medical transportation of .23/mile

(<https://www.irs.gov/Tax-Professionals/Standard-Mileage-Rates>)]. You could also add any hotel stays and costs of meals that you will have in transit to the conference.

## TAXES

Don't forget that, even if you aren't able to find a grant to assist you, some of the expenses you incur in travelling to a conference at which medical information is shared is CURRENTLY tax deductible if you itemize your medical expenses on your federal tax return. See "medical conferences" here for current rules: <https://www.irs.gov/publications/p502/ar02.html>.

**We hope that these resources are helpful, and please let us know if you are successful in obtaining a grant, as we would like to keep track of funders who have been supportive.**

## **Crowdfunding Tips for 2018 Family Conference**

*After researching several crowdfunding sites, we think the best option for 22q families who would like to raise money for 2018 Family Conference is to use YouCaring. Unlike other crowdfunding platforms (like GoFundMe), YouCaring does NOT have a fee. So in other words, you can raise money for your child without having to worry about a large percentage getting taken out at the end!*

### Tips to a Successful Crowd Funding Campaign

- **Learn from great storytellers**

Before you tell your own story, it's a good idea to explore successful YouCaring fundraisers for examples of courageous storytelling. Take a look at Finley's miracle surgery to get her dancing legs (<https://www.youcaring.com/finley-582947>), K9 for Alvin (<https://www.youcaring.com/pet-expenses/k9-for-alvin/164072>), and Save Dave (<https://www.youcaring.com/davidkay-868644>).

As you experience these pages, ask yourself these questions:

- o How do these stories work to create understanding and empathy?
- o What can you learn from their approaches to storytelling?
- o For each story, are there any specific aspects that made you feel strongly?
- o What emotions do you want your own story to convey?

- **Get started**

Start with a sentence that introduces yourself and the "main characters" of your story. Give readers (potential donors) the most relevant information first. How do you define yourself in relation to your story, or to the beneficiary? Whether it was your role as a parent, an entrepreneur, an environmentalist,

or a cancer survivor, what was it that led you to start this fundraiser? For now, keep this introductory information brief—you can always add more context if it becomes relevant later.

Example: My name is \_\_\_\_\_, and I've spent my life \_\_\_\_\_.

- **Define the essential pieces of your story**

Start by identifying the elements you need to tell your crowdfunding campaign story fully. Note which details you have, and which you may need to find or develop. Make a list of photos and videos that exist, and ones you could create. What details will make your story come alive?

Your story needs to answer basic questions any reader would have: who, what, where, when, why, and how. What will the funds be used for? How are you connected to the cause? How will the donations raise aid you or others? When it comes to fundraising, the why is particularly important—why does the recipient need this donation?

Other essential aspects of telling the story of your cause include an inspiring title; a clear goal; a deadline; and specific, compelling details. Together, they can paint a unique, personal, and compelling picture that inspires others to give.

Example: My life changed dramatically when \_\_\_\_\_.

- **Share your history**

If you've tried other solutions before crowdfunding, it may be a good idea to share what you've done so far. How have you or your loved ones attempted to overcome the challenge presented to you? What hurdles have you faced, and how have they changed you as a person? Take this opportunity to describe the effect of your struggle on your family, your local community, or society as a whole. Feel free to add more context now that readers have the basics.

For a good example of this stage of storytelling, take a look at the updates section in the Help Save Matthew! campaign. By highlighting the ups and downs of Matthew's tumultuous battle with cancer, his wife Katia helps potential donors invest emotionally in the outcome of his treatment.

Example: When \_\_\_\_\_ happened, we made a choice to \_\_\_\_\_. And then \_\_\_\_\_.

- **Emphasize the turning point**

What event led you to take action and start crowdfunding? Whether that moment took place in the boardroom, in a doctor's office, or at the kitchen table, summarize it in a sentence or two.

Example: It was at that point, when \_\_\_\_\_, that we realized that we needed help from our community.

- **Show why we should care**

This is the main question in the back of a potential donor's mind, and the most important question your story should answer. In books and movies, the audience cares about characters who want something badly, and have (challenging yet surmountable) trouble getting it. People often feel a connection to imperfect characters who are doing their best under extreme circumstances.

We often turn to crowdfunding after a tragedy, either our own or someone else's. In such situations, telling one's story requires courage and honesty. One fundraising story told with incredible courage was Riley Sandler's. Riley's parents conveyed her personality and spirit in the face of a great loss. It can be scary to broadcast your most vulnerable moments to the world, but your honesty allows people to form a human connection with you, and with the beneficiaries of your fundraiser.

- **Build the story of your fundraiser**

Beyond the overview, which parts of your story demand attention? What aspects will keep people reading—and motivate them to donate? Write your story with these elements highlighted, then add supporting details to connect the dots.

Once you've done this, step back and examine whether each part of your story works hard enough for your cause. How does each sentence, and each image, deepen interest in contributing? Does the flow of the narrative keep readers curious enough about what happens next that they'll read your entire story, then want to lend support?

- **Sharpen your story**

Take a few minutes to write down how you feel about your cause. What are the most accurate and heartfelt words you can use to describe the need for help? Then look at your fundraiser description—are those words clearly featured in your story? Look at your story from the perspective of potential donors.

- **Title your fundraiser**

It's hard to overstate how important the title of your fundraiser is. As with the title of a book or movie, it can draw people in or turn them away, before they know anything else. It's the first thing people see on social media, the headline of your fundraising page.

Waiting to come up with a title for your fundraiser after you've written your story can help you capture your campaign in one standout line or phrase. Also, when you tell your story first, you're more likely to see your fundraiser title as a story title.

Whether you're drawn to a humorous approach—Jen's Tumor Eviction Fund—or a more straightforward one—Save Allison (New Mother with Brain Cancer)—the title should include the name of the beneficiary (the main character of your story) and highlight the major challenge that person is facing.

Example: "Help \_\_\_\_\_ Knock Cancer Out!" or "Fund \_\_\_\_\_ 's Heart Surgery"

- **Get feedback and refine**

Read your story aloud to see how it sounds—to yourself and to others you trust. Does it sound like you're telling the story to a friend? Are there any moments where it feels stilted or dishonest? Which parts inspire readers to care enough to make a donation? Would you personally be inspired to share this story?

One option to consider is telling your story in sections with subheadings—just as this post has been presented. This approach can make it easier for people to understand and absorb information. When you're happy with the results, look through your story a few more times, removing any errors. If you

have someone in your life with strong editing or proofreading skills, ask him or her to review your story and make sure it's as good as it can be.

- **Write frequent updates**

If you view each donation as the beginning of someone caring, not the end, you can see the importance of posting updates. As you post updates, you bring donors into an unfolding story. And when potential donors see this, it inspires them to become part of the story as it unfolds.

We see a direct correlation between the frequency of updates and the volume of funds people raise. Update your donors often. In your updates, share good news as well as hardships, and do so as often as you might fill in a close friend. See this blog post for tips on how to write a fundraising update.

- **Add photos and videos**

Not only do photos and videos make your story more personal, they also help other people share and tell your story. Include photos and video in each update you post for donors.

- **Remember, honesty wins**

Always be honest. Authenticity invites people to care enough to lend a hand. By telling your crowdfunding campaign story with clarity and heart, you inspire compassion. Don't be afraid to be vulnerable when you share details. Help people understand how much their donations help.

