

Attending a conference requires a lot of planning and funds for families. Past attendees have told us that being at the conference is “life changing”.

We hope you find resources to help you with your trip. These resources apply to the United States. If you know of other sources in the US or internationally that we can share, please contact us at conference@pmsf.org.

In this Resource Guide, you will find:

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Helpful Hints:

1. Prior to completing any application for funding, contact the organization to which you are planning to apply for support to ensure the program still exists and your request would be eligible.
2. If you need verification from the Foundation about the 2024 event to provide to the potential funder, you can share our conference website link <https://pmsf.org/conference>
3. Complete the necessary paperwork or online forms and submit prior to any published deadline dates. Follow all instructions provided by the organization.
4. If you are awarded a grant, send a thank you note to the organization.

Support for air travel - [TSA Cares:](#)

Make sure you [complete this form](#) to register for this service while traveling. It is different in each airport, so, register as soon as you know your travel plans. Our families have found this resource extremely helpful while traveling. It is a helpline to assist travelers with disabilities and medical conditions. TSA recommends that passengers **call 72 hours ahead** of travel for specific information about what to expect during screening.

These agencies offer grants to families to defer conference travel expenses.

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 six week turnaround: http://www.prayerchild.org/submit_request.html.

State or Regionally Limited:

- **Medicaid Waiver** - If your child or adult with PMS is on the [State Medicaid waiver](#), you may be able to apply for funding to cover the conference registration. Talk with your service provider/case manager/support broker to learn if there is funding available.
- For **Chicago-area** families, 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.
- 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 & adults with special needs. <http://www.hannahandfriends.org/resources/hannahs-helping-hands-grants/>
- For eligible **Iowa** families, the Children at Home Grant may be used to cover some of the costs related to parent/guardian education, which includes the PMSF conference. Families may apply at any time. [Children at Home - Iowa Family Support Network \(iafamilysupportnetwork.org\)](http://www.iafamilysupportnetwork.org)
- You may wish to contact your University Center for Excellence (www.aucd.org) and Protection and Advocacy groups. Often these groups will have a fund to provide family support and education through conferences.
- If you have a flexible spending account, you may be able to get conference expenses covered.
- Disability Info.org lists some grants and funding sources: <https://disabilityinfo.org/>
- The AMCSI Support Group is for a different syndrome, but their website does list some useful state Developmental Disability links. <http://www.amcsupport.org/KCcif.htm>
- Family Voices (www.familyvoices.org) is a national group that may be able to help you find grant money within your state.

- Local community and service clubs in your area may provide sponsorships or scholarships to families. Many have grant deadlines so begin your search right away. These clubs include, but are not limited to:

Optimist	Rotary	Masons
Lions	Junior League	Knights of Columbus
Kiwanis	Eastern Star	Moose Family Fraternities
- If you're a military family, the VFW and American Legion may be a resource.
- Contact local providers in your area such as Early Steps Program, Easter Seals, or other support groups to which you may belong.
- Contact your local Parent-To-Parent organization and ask them if they know of any support networks that will assist in the conference. Parent-To-Parent information can be found under the PACER grant link at www.pacer.org.
- Your local church or temple may offer financial assistance.
- Your local or state Autism group/organization may offer funds. Additionally, The Autism Society's resource database (www.autismsource.org) allows you to search by location or service type for resources throughout the United States.
- Look for state or county managed organizations that may assist families with children with disabilities.
- The United States Department of Health and Human Services Administration on Developmental Disabilities partners with other agencies. Find those in your state.
- Your local school Exceptional Student Education (ESE) department, Student Services Department, or Area Education Agency may know of resources.
- The National Dissemination Center for Children with Disabilities is a federally funded program that serves as a central source of information on resources available to individuals with disabilities. The [website](#) will have links listing different agencies serving your state.
- Contact your city, state, or county's inclusion network which may be found through your State Department of Education.
- United Cerebral Palsy: Contact your [local UCP affiliate](#) to find family support information and resources. If there is no affiliate in your area, call 800-872-5827 or send an email to info@ucp.org.

Councils on Developmental Disabilities:

All states have a Council. They are a planning and advocacy organization committed to community inclusion for people with developmental disabilities, and some will fund conference travel (and often have other great resources for families, so check yours out!). Some states require that you agree to share the knowledge you gained at the conference with other groups in your state (and we would recommend that you target schools/classrooms with other students with DD as your point of sharing. If your state is not listed below, you should take a minute to review your own state's CDD page

<https://nacdd.org/councils/>

- 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>.
- 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. Indiana Governor's Council for People with Disabilities has the Consumer Education fund, found here: <https://www.in.gov/gpcpd/2328.htm>
- 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 90 days prior to conference: <http://www.md-council.org/funding/conference-participation-fund/>.
- Nevada: The Governor's Council on Developmental Disabilities provides grants of up to \$750 for individuals and \$1000 for families to attend conferences out of state. No deadline provided, so call contact on the webpage for details on timing: <http://www.nevadaddcouncil.org/consumer-leadership-3/>.
- North Carolina: The state's Jean Wolff-Rossi for Participant Involvement Fund offers up to \$800 per person (and up to \$1800 per family) for participation in out-of-state conferences. Deadlines for application are 60 days prior to registration date for an out-of-state event; decisions are made monthly on an ongoing basis: <http://nccdd.org/initiatives/conference-funding/rossi-fund.html>.
- North Dakota: The State Council on Developmental Disabilities has a Consumer Leadership Fund that supports family participation in conferences, up to \$750 per individual or \$1000 per family; they do require that grantees share experiences with the SCDD or other advocacy organizations in the state. Deadline is 90 days prior to the event: <http://www.ndcpd.org/SCDD/pdf/2016/Consumer%20Leadership%20Development%20Fund%202016%20Combined.pdf>.
- South Dakota: The state's Council on Developmental Disabilities provides funding up to \$750 per person for out-of-state conference travel, but the applicant must show that other funders have been approached with no success. Deadline is 60 days prior to the event: <http://dhs.sd.gov/ddc/stipnd.aspx>.

- 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> and here for the application link: <http://www.tn.gov/cdd/article/education-travel-fund> .
- Utah has an Empowerment Fund designed to support family attendance at disability-related conferences, but the information has not been updated since 2009. If you wish to pursue this, call first to make sure that the funds are still available and procedures are clear. <http://www.utahddcouncil.org/grants/empowerment/index.html>
- Vermont: The state's Developmental Disabilities Council provides grants of up to \$500 for families of people with disabilities to travel to conferences. Deadline is 30 days prior to the conference: <http://www.ddc.vermont.gov/grant-information>.

Preparing to Apply:

If there isn't a form . . . here are some tips:

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.

1. 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 Phelan-McDermid Syndrome Foundation International Family Conference in Bloomington, Minnesota, July 17-20, 2024."
2. Introduce your child and explain Phelan-McDermid Syndrome: "My child, _____, is _____ months/years old and has Phelan-McDermid syndrome (PMS). PMS is a rare genetic condition caused by a deletion or other structural change of the terminal end of chromosome 22. The symptoms of PMS can cause a wide range of medical, intellectual, and behavioral challenges. The most common characteristics found in those with PMS are intellectual disability, delayed or absent speech, symptoms of autism spectrum disorder, low muscle tone, motor delays, and epilepsy. There is currently no cure or treatment specifically for PMS, but families and researchers are working hard to improve our knowledge of PMS to help people affected by PMS. Details about the syndrome can be found at the Phelan-McDermid Syndrome Foundation website: <https://pmsf.org>
3. [If you wish, add a few details here about your child's personality or the severity of the presentation of symptoms, etc..]"
4. A statement of the costs: How much will it cost (see #6, below, for the detailed budget, 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.
5. 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 Phelan-McDermid syndrome. The conference will also provide enormous family support as we make connections with other families affected by this very rare, and sometimes isolating, disorder." [You might also indicate if your child has siblings who would be attending and if that would be a particular benefit.]
6. Procedures of the conference: "The Phelan-McDermid Syndrome Family Conference will last four days. Educating families on the current Phelan-McDermid Syndrome(PMS) research and family support practices to help them improve the lives of their children and family is a primary goal of the conference. This year attendees will focus on research updates on Clinical Trials, Behaviors, Regression, GI Dysfunction, Seizures and Genetics. Professional speakers will provide information on important topics such as educational planning, transition to adult medicine, managing behaviors, applied behavior analysis, developing communication, adult living options, legislative advocacy, family support for everyone impacted by PMS. Sessions often include panels of experienced caregivers to help engage and educate attendees on best practices, successes and challenges in caring for a child with PMS.
7. Include a link to the conference website: <https://pmsf.org/conference>.
8. A detailed budget: "Our plane tickets will cost \$_____. Taxi fare from the airport (round trip) will be \$_____." Or, "We will be driving our accessible van _____ miles to the conference and back.

Mileage expenses for the trip will be _____

.(<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.

9. A [conference budget worksheet](#) is available to calculate expenses.