



CHARGE Accounts

The mission of the CHARGE Syndrome Foundation is to lead and partner to improve the lives of people with CHARGE syndrome locally, nationally and internationally through outreach, education, and research.

OFFICERS

President: David Wolfe
Vice-President: Lisa Weir
Treasurer: Brownie Shott
Secretary: Neal Stanger

DIRECTORS

Julie Brandrup
 Karin Dagley
 Minnie Lambert
 Joanne Lent
 Christian Lobaugh
 Amrit Mehta
 Pamela Ryan

SPECIAL ADVISORS

Meg Hefner
 Donna Martin

DIRECTOR OF OUTREACH

Sheri Stanger

DIRECTOR OF ADMINISTRATION

Jody Wolfe

DEVELOPMENT & DATABASE MANAGER

Jackie Alshawabkeh

The CHARGE Syndrome Foundation, Inc.
 318 Half Day Road
 Buffalo Grove, IL 60089
 800-442-7604
www.chargesyndrome.org
info@chargesyndrome.org

Special Conference Issue

President's Message

As we prepare to Take CHARGE in Orlando, many thoughts enter my mind. I remember the overwhelming flood of emotions I felt at my first conference in 2003. There are so many special memories from all of the conferences my family attended. While no two conferences are ever the same, all seven I have attended were special in their own way. I would not want to miss any of them!

I am proud of how our CHARGE family continues to grow and evolve. Our special Conference Issue highlights what to expect at conference and addresses many of the frequently asked questions and concerns. There will be something for everyone as we join together and Take CHARGE in Orlando.

In the midst of all the Conference excitement it is very easy to assume that the Foundation will always be there: underwriting more than \$200,000 in conference expenses; increasing clinical and genetic research funding; reaching out to new families; connecting other families and doing the many other things we have grown to expect. It is understandable to take all of this for granted.

We need your help this holiday season. Please make sure we all do the best we can to help the Foundation. Renew your membership, donate as generously as possible, fundraise, and volunteer as much as you can. Take CHARGE now.

Happy Holidays. See you in July,

David

David Wolfe, President

Happy Holidays



CELEBRATION, HOPE, ANTICIPATION, RUN-DOWN, GLEE, EXCITEMENT ...

You'll Feel It All At A CHARGE Conference!

As both the Director of Outreach and a parent of a young adult with CHARGE, I'd like to offer you some insight into the feel of a CHARGE syndrome conference and how it may feel to you. No one experiences conference in the same way. You may be new to the world of CHARGE syndrome or involved in it for 30 years but there's still something that attracts people to this particular conference. I believe it's the feel of the conference, the feelings of hope it brings to families and the knowledge that your family and child are accepted at this conference – no questions asked! No stares and no judgment.

As you've probably heard, the conference offers general sessions, breakout sessions, social events, activities and camp. Even down time is built in to the conference so families can spend time together in an unstructured way. It's a lot to ask of a conference to do all these things, but somehow its been achieved. And the Foundation always strives to do better and make it meaningful to all families and professionals in attendance.

The reality is, not every event is for everyone and you shouldn't feel like you need to do everything. You can pick and choose what you need to do and what you need to hear. If anything becomes too overwhelming for you or your child, it's ok to take a break. This conference is for you and it is why we try to offer so much in only a few days time.

As a new parent or a first time attendee, or a person with CHARGE or a professional attending for the first time, you will certainly be feeling some hesitation prior to conference. You'll have no doubt been hearing lots of chatter on Facebook about the conference and how excited everyone is to attend. And it's true – they really are excited and you want to know why!

People genuinely love to spend time together. Our kids, no matter what age, are celebrated. We see the potential in our kids despite their challenges. And it's not just the kids with CHARGE syndrome. Our families are celebrated! The conference reminds us that we are important in our child's life and our whole family's life. It reminds us how special the siblings are - their needs and the role they play in the family. It reminds us that parents also need to take care of themselves. It reminds people of how critical it is to stay involved and informed – to stay connected to the Foundation and to other families that understand our day-to-day lives.

We are also reminded of the critical role the professionals play in our lives. There will be many medical, educational and therapeutic professionals at the conference. They are part of the CHARGE family as well. They are there to present their knowledge and they are there to learn. They want to speak with you. And if you're a professional attending for the first

CONFERENCE AT A GLANCE

Thursday, July 27

Professional Day
8:00 – 5:30

Pool Party! 2:00 – 4:00
Opening Reception 6:30 – 9:00

Friday, July 28

Sessions 9:00 – 5:00
Camp (full day)
Exhibitor Fair and Poster Presentations
Signing Time with Rachel Coleman

Saturday, July 29

Sessions 9:00 – 5:00
Camp (full day)
CHARGE-A-Palooza
Silent Auction & Basket Raffle

Sunday, July 30

Presentations 9:00 – 12:00
Camp (half day)

time, don't be afraid to ask questions – we love to talk about our kids! We want people to learn more about CHARGE syndrome and spread awareness.

I'll tell you a bit about my first conference. I have a 23 year-old daughter with CHARGE syndrome. My first conference was the 2nd International CHARGE Syndrome Conference in Portland, OR back in 1995, when my daughter was almost 2 years old. We had no idea what to expect. This was before social media! We knew the agenda and that there would be childcare and that we'd be staying in college dorms! We've come a long way from dorms to a resort setting, but I'll never forget my first conference and it will always be my favorite in many ways, despite the heat wave in Portland and the lack of air-conditioning. It holds special memories for me because it was the first time I was with so many people in one place who had a child with CHARGE syndrome. And I'll never forget my conversation with a family that had a 15-year-old son with CHARGE. I saw how well he was doing and he held my daughter and talked with us. And I knew that things were going to be ok. Not easy, but ok. There was hope! It was also the first time I met David Brown and Rob Last and realized there were professionals interested in our families and kids who were willing to spend as much time with us as necessary to understand our needs.



The conference can be an emotional roller coaster. You will feel lifted up one moment and sometimes you will be in tears. But that's ok! It's part of the experience. You may be overwhelmed at times but you will also feel energized and armed with new information and support systems!

The Foundation has come a long way with conference planning. While the conferences have certainly grown in size, we try to maintain that intimate family feel. It may seem that everyone knows each other – and many do! Yet there are always many new families in attendance. The Board of Directors and the State Parent Liaisons will be available to help you navigate the conference. They will help connect you to other families – even prior to conference if you wish. Soon, you too will be chatting with new friends and planning for the next conference.

Please know that I am always available to talk with you about conference and assist you with resources, information and family connections. I look forward to meeting you in FL next summer as we Take CHARGE In Orlando!

Sheri Stanger, Director of Outreach
1-855-5CHARGE (855-524-2743)
or sher@chargesyndrome.org.

Don't miss a single detail.
Ensure you are receiving foundation emails.
Sign up for eNews.

Learning Together

We hope you can join us as we Take CHARGE in Orlando! We will have a top notch program with a wide variety of speakers who are the leading experts in CHARGE syndrome. The four general theme areas under which most sessions are organized include: behavior, education, adult issues, and medical. There will be something for everyone!

General Sessions

We begin each day, in general session with everyone together in one large room. During the general sessions, we have a keynote speaker on Friday, awards and Foundation updates on Saturday, and our always-popular Adult Panel and closing talk on Sunday.

Breakout Sessions

After general session on Friday and Saturday, we have a short break and then the breakout sessions begin.

(There are no breakouts on Sunday as the program closes at noon after general session.) The breakout sessions happen during the rest of the day. Everyone will split up and go to whichever breakout session interests them. There are up to six sessions happening at the same time. The schedule and handouts will be available online prior to conference and will be helpful in terms of making decisions about which sessions you might want to attend. Some families decide to “divide and conquer,” splitting up and going to different sessions when there is more than one session happening at the same time that the family would like to attend.

Information Central

On Friday afternoon, we also have our “Information Central” session. During this time, you can browse posters and speak to the many wonderful professionals who are at the conference. If you have questions, this is the time to find the professional who can help!

Conference Handouts

I highly recommend that everyone have a look online prior to conference at the handouts and conference schedule to try and get a preliminary idea of sessions you might want to attend. It can be a lot to figure out once you get to conference after traveling with family, trying to getting settled at the hotel and so on. Also, please ensure you are receiving emails from the Foundation (you can [sign up for eNews here](#)) so that you get notifications about when the program schedule and handouts are available. Download the handouts onto your phone, computer, or tablet (or print if you prefer) so you are ready to roll when you get to conference!

If you have any questions about the program, please [email me](#).

Lisa Weir

Lisa Weir, 2017 Program Chair



Being Together

The sessions may take the most time in the Conference schedule, but we all know the backbone of our conference is simply being together. Where else can you find hundreds of people who are so knowledgeable and passionate about CHARGE syndrome? The special conversations and commonalities shared between families, professionals and education experts are truly precious and priceless takeaways from the event.

In 2017, as we are Taking Charge in Orlando, plenty of social time has been included in the schedule.



As weather permits, we hope take advantage of the beautiful patio and pool areas of the Rosen Shingle Creek resort as often as possible, but especially on Thursday afternoon. From 1:30 to 4pm, a private pool has been reserved for our Welcome Pool Party. This is sure to be a great time for all - and a great way to prepare for the rush of Conference!

Thursday night is our official opening kick-off reception from 6-9pm, with appetizers and light dinner being served. As in the past, this will also be a time to break out into smaller groups.

After our first day of sessions on Friday, dinner will be another opportunity to reacquaint with old friends or meet new ones. This year, we are excited to announce a very special guest entertainer. Back by popular demand - and thanks to the Texas CHARGERS - Rachel Coleman, our favorite yellow-sweater-wearing star of "Signing Time" will perform an ASL-themed concert. Afterwards, she will be available for autographs and photos with her fans. If you would like to find out more Rachel's story, please visit the Signing Time website.



Our final night, Saturday, features the blowout party CHARGE-A-Palooza, with music, dancing, games, face-painting, and fun photos. Everyone will be in the mood to celebrate our time together and all we have learned. This is also the night you can support the CHARGE Foundation and leave with great items from the ever-popular basket raffle and silent auction.

We hope all attendees will enjoy these planned social events. The CHARGE syndrome community, perhaps more than any other group, appreciates the unique camaraderie we all share and having this time together to learn from and support each other. See you in Orlando!

Donate a basket for Saturday night's CHARGE-A-Palooza

More baskets = More Winners = More Fun!

We need baskets for adults and for kids of all ages and abilities, with a value of at least \$50 (date night, game night, spa day, chocolate lovers, sensory toys, etc.). We are also accepting high-end items, such as timeshares, fine jewelry, airline tickets, electronics, and sports memorabilia.



Check the [Conference Events page](#) for the donation form and letter or contact [Neal Stanger](#) for more information.



Professionals

The CHARGE Syndrome Conference is unique in that experts in the field are available to speak with families throughout the weekend. The respect is mutual. Professionals learn as much from families as families do from them.

Professional Day

The CHARGE Professional Day Conference is on Thursday, prior to the start of the International CHARGE Syndrome Conference. Professional Day is an opportunity for CHARGE professionals to come together to share information, research and best practices with one another and the presentations are specifically for that audience. This one day conference includes plenary presentations of interest to all professionals, breakout sessions in the areas of Medical/Clinical and Educational/Therapy, and time during the poster session, lunch and breaks to allow meeting and mingling among CHARGE professionals. Most of these professionals will stay on for the International Conference and many will be presenting their information at the International Conference with their talks geared toward families and individuals with CHARGE. The registration fee for attendance at Professional Day is \$175.

If you are or know of professionals who may be interested in presenting at or attending the CHARGE Professional Day, see the Call For Presentations and Registration information at the CHARGE Syndrome Foundation website.

Posters & Information Central

There is always more information available than we can fit into the presentation slots at the CHARGE conferences. And no one can always make it to every talk they are interested in. That's why we have Posters and Information Central. Professional Day (Thursday) includes a Poster session after lunch. The International Conference has a Poster session as part of Information Central on Friday afternoon. There, you can see posters describing some of the CHARGE research and summarizing some of the presentations. Authors will be at their posters so you can ask questions and get information. Information Central will also have exhibits from various groups you should know about and maybe even some demonstrations or events to participate in.

Research

We all want to learn more about CHARGE, and that means research. Because CHARGE is relatively rare, most professionals only see a few affected individuals in their local practices. Conference attracts hundreds of individuals with CHARGE and their families, providing a wealth of potential research opportunities for the researchers and for families. Previous conferences have included everything from collecting DNA to interviews about feeding, language and behavior. There will be an area dedicated to the various research projects being conducted at conference.

What can you do now?

If you may want to conduct research at the upcoming conference, please contact Meg Hefner meg@chargesyndrome.org (put "CHARGE research" in the subject line) with a brief description of what you would like to do. Meg will get you on the mailing list for potential conference researcher.

If you may want to participate in research, watch for emails prior to conference for details. Right now, you can enter baseline information, online, in the CHARGE Syndrome Clinical Database Project (CSCDP). This baseline information can be used to find appropriate subjects for research and can be shared with other researchers to avoid many duplicate questions later. Information on CSCDP and how to get started is here: <http://chargesyndrome.org/CSCDP.asp>

Sandra Davenport Fellowship Program

The Davenport Fellowship program was established in 2015 to facilitate mentoring of the next generation of CHARGE professionals. By bringing the Fellows to the CHARGE conferences early in their careers, we hope to educate the next generation of professionals and encourage them to become more engaged with the greater CHARGE community. The CHARGE conferences are the best opportunity for professionals to learn more about CHARGE, to interact with one another and get to know families. Davenport Fellows may include graduate students (genetic counseling, psychology, therapy, etc), medical students (upper level students, residents or fellows), and other professionals who will deal with individuals with CHARGE during their careers. The Fellows will attend both Professional Day and the International Conference and meet each day with each other and the mentors for the program (Meg Hefner and Pamela Ryan). Each Fellow will also be matched with a family and spend a half day in Camp with the child from that family. Some may have presentations or posters during the weekend. If you know of a professional who may be interested in applying for a Davenport Fellowship, see the link at the website.

Call for Presentations

The CHARGE Syndrome Foundation is seeking proposals from presenters and speakers for the 13th International CHARGE Syndrome Conference, which will take place July 25–28, 2013, in Orlando, FL. The conference serves as a venue to provide information to individuals with CHARGE syndrome, their families, and professionals. The event begins with Professional Day, followed by 2-1/2 days for the full conference. While there are various opportunities to make presentations, presenters are urged to present at both Professional Day and the full conference. The deadline for Submission is January 31, 2017. [Complete information is available on our website.](#)



13th International
CHARGE Syndrome Conference
July 27 - 30, 2017
Call for Presentations

Exhibitors, Sponsors and Advertisers

We are actively looking to add exhibitors, sponsors and advertisers to our event. The Conference provides a unique opportunity for companies to reach hundreds of families affected by CHARGE syndrome and the professionals who work with them. We expect over 1,000 people to attend!

If you, or someone you know, should exhibit, sponsor or advertise at the 2017 conference, please contact:

David Wolfe at david@chargesyndrome.org or
Brownie Shott at brownie@chargesyndrome.org



Camp

We are pleased to offer a camp program for individuals with CHARGE and their siblings. Corporate Kids Events (CKE) will run our onsite camp and will provide fun, entertaining activities for the kids while the adults attend conference sessions. Arts and crafts, magic shows, and petting zoos have been part of the camp program during prior conferences. There are two camp options: Camp Discovery and Camp Explorer.

Camp Discovery has a higher staff to camper ratio (less staff per # of campers), for siblings and more independent campers.

Camp Explorer has more structure and more staff.

- Both camps will be together for certain activities.
- There will be a professionally-staffed calm room containing sensory items and a soothing atmosphere, which will be available if campers need a space/time to calm down.
- Camp is free for all individuals with CHARGE but all campers must be registered with CKE.
- Registration for camp will open at the same time as conference registration, in early 2017.
- Your caregiver may attend camp with your child. The caregiver must be registered for conference.

Signing Volunteers Needed!

Many of our children with CHARGE use sign language to communicate, but we typically have fewer signing volunteers in camp than we need.

Can we count on you to recruit your child's teachers and therapists, and your friends and family to make camp accessible and fun for all?

Email joanne@chargesyndrome.org to volunteer or for more information



Having a brother or sister with CHARGE is not always easy. Sibshops provides siblings aged 8-13 a safe place to meet, share - and just have fun - with other siblings who know exactly how they feel.

SPACE IS LIMITED

Members get priority at registration

The Hotel

We are thrilled to be returning to the gorgeous Rosen Shingle Creek Hotel in Orlando. The hotel is a fantastic meeting and vacation destination, conveniently located near Orlando International Airport, Disney World, Universal, and Sea World.

Families will love the spacious and comfortable guest rooms with mini-refrigerators and complimentary Wi-Fi, the four shimmering heated pools, a golf course and spa, the numerous options for meals and snacks, and the many other amenities the hotel offers.



Use this link to ensure you get the reduced rate of \$149: [Rosen Shingle Creek Hotel](#).

**The conference rate is available from July 22nd to August 6th
if you would like to extend your stay. You can make your room reservation today!**

Upgrades and Special Requests — Please contact the hotel directly at 407-996-6338 for suite upgrade rates and other information. ***Make sure to tell them you are with the CHARGE Syndrome Conference.***

Meals

All meals and snacks during conference are included. No food is provided or permitted in camp



Thursday:

Snacks during pool party. Appetizers/light dinner during welcome reception.

Breakfast and lunch for Professional Day attendees.

Friday & Saturday:

Buffet breakfast, lunch & dinner

Sunday:

Buffet breakfast.

Soft foods (yogurt, pudding, applesauce), blenders and microwaves will be available at all meals.

Questions? Special diets?

Email info@chargesyndrome.org

Orlando Area

Theme Parks

If you come early to the conference or stay late, Orlando's theme parks are a fun adventure for the whole family. You can purchase discounted multiple day passes to many local theme parks at the hotel's guest services desk. The hotel offers complimentary shuttle service to Universal Studios, Sea World, and Aquatica.

If you have Disney World in mind, please note that the Rosen Shingle Creek Hotel does not sell tickets for Disney or provide transportation to the park. (We suggest you visit disneyworld.disney.go.com for ticket information on Disney World.) You can arrange for shuttle service to Disney World from the hotel through Town and Country Transportation for about \$18 per person by calling them directly at (407) 828-3035.

Orlando is very hot in July, so plan your outdoor adventures accordingly.

Transportation From/To Orlando International Airport (MCO)

The Rosen Shingle Creek Hotel is approximately 20 minutes by car from Orlando International Airport. *Please Note:* Neither the Rosen Shingle Creek Hotel nor the CHARGE Syndrome Foundation provides transportation between the airport and the hotel.

Unless you plan activities outside the conference, there is no need to have a car during your stay. Instead, consider taking a shuttle van or taxi to and from the airport. Expect to pay approximately \$20 per person for a shuttle and approximately \$46 for a taxi (4-5 people).

For more info on shuttles and taxis, visit: rosenshinglecreek.com

Driving or Renting a Car

If you drive or decide to rent a car, you can self-park for a reduced daily fee of \$9.

If you need a car during your stay, Enterprise Rent-A-Car rental is located at the hotel.

Grocery Store & Pharmacy

Publix supermarket is located just across the street from hotel entrance, but it is at least a 10-15 minute walk. They do not have a pharmacy.

Walgreens pharmacy is a bit farther up the road, about a 20-minute walk: 9650 Universal Boulevard (407) 956-8453

Medical Care

Orlando has excellent medical facilities. The closest children's hospital to the hotel (about 8 miles away) is Arnold Palmer Hospital for Children, 92 W Miller Street, Orlando (407) 649-9111.



Sign up for e-news and check the [conference information page](#) for announcements and the latest updates on registration, program and events

Registration

Online registration for the 13th International **CHARGE Syndrome Conference** will begin in early 2017. All individuals with **CHARGE** attend conference for **FREE**.

ALL LIFETIME MEMBERS RECEIVE A 10% DISCOUNT OFF CONFERENCE REGISTRATION FOR THEIR IMMEDIATE FAMILY ONLY.

To become a lifetime member, to join or renew your annual membership, [please click here](#). Your membership provides your voice to increase awareness, educate others, and encourage research.

Registration Rates if paid by June 1:

Professional Day:	\$175
Individuals with CHARGE:	FREE
Children (12 and under)	
NOT attending camp:	\$225
Children attending camp:	\$325
All other individuals (13 and up):	\$325

Late Fees:

June 2 – July 15: Add \$50 per person
July 16 – onsite: Add \$100 per person

We want all of our families to be able to join us as we *Take CHARGE* in Orlando and are pleased to offer scholarships and a new incentive program that enables you **FREE** conference registrations and **FREE** merchandise. We also created a conference funding guide to assist you as you seek financial support from local and national agencies.

Scholarships

First-time conference attendees can apply for the **Norbury Scholarship**, a tribute to Marion Norbury, founder of the CHARGE Syndrome Foundation, and her husband Lee, who supported her work.

The **CHARGE for Connor Scholarship** was created in memory of and tribute to Connor Logsdon by his family. The scholarship supports families who need help with hotel costs.

Anyone can apply for the **CIFC Scholarship**, which is supported by the annual **CHARGE It For CHARGE** fundraising campaign. Preference is given to current or past CIFC fundraisers.

ONLY FOUNDATION MEMBERS MAY APPLY FOR SCHOLARSHIPS.
BECOME A MEMBER BY APRIL 1, 2017 TO BECOME ELIGIBLE FOR A SCHOLARSHIP.

CIFC Incentive Program

- Raise \$500 to receive a free conference T-Shirt
- Raise \$1,000 to receive a free T-shirt and sweatshirt
- Earn a free conference registration for every \$2,500 raised (up to 4)

Support the Foundation. Click Here to Start Your CIFC Fundraising Campaign!



Levels:

Raise \$2,500 - Earn one (1) Free Conference Registration, Conference T-Shirt & Sweatshirt

Each Additional \$2,500 Raised - Earn An Additional Registration (Up to maximum of 4 free registrations)

Raise \$1,000 - Receive Free Conference T-Shirt & Sweatshirt

Raise \$500 - Receive Free Conference T-Shirt
(Limit one (1) T-Shirt & one (1) Sweatshirt Per Fundraiser)

Conference Funding Guide

We would like everyone to have the opportunity to attend a CHARGE Syndrome Foundation Conference and are aware of concerns about being able to afford the full cost of attending the conference. In response to these concerns, the Board has taken to the Internet to seek sources of funding that you might be able to tap to help you fund your trip. We have identified a number of organizations that offer grants to individuals and to families of children with developmental disabilities.

Our primary source of information was Wonder Baby.org, a website published with the support of the Perkins School for the Blind (<http://www.wonderbaby.org/articles/ipad-funding-special-needs> and <http://www.wonderbaby.org/articles/conference-fundraising#proposal>).

The first link provides some wonderful information on ways to get money to purchase specific items such as iPads from insurance companies, schools, local charities, fundraisers, and grant applications to specified list of organizations.

The second link gives more great hints on how to go about getting a sponsor/advocate and writing a successful proposal letter to request financial aid for attending a conference. Using this article as a guide, we developed a sample letter specifically focusing on obtaining funding to attend the 2017 CHARGE conference. (Available at <http://www.chargesyndrome.org/wp-content/uploads/2016/11/samplegrantletter.pdf>.) We hope that you will find it a good starting place for your own letter. We also created an [Excel spreadsheet](#) that you can use to calculate your family's travel and

conference costs. Your detailed, categorized conference related expenses can then be attached to your funding applications and letters.

Using the lists of organizations found in these two Wonder Baby articles, we exercised our online search engines to learn more about them. We researched organizations that offer grants to individuals and families. Some have significant geographic limitations or membership in specific ethnic groups while others have national and international service coverage. We attempted to summarize information about these agencies, how to contact them, specific information about their grant processes and application deadline dates (where available). (Available at <http://www.chargesyndrome.org/wp-content/uploads/2016/11/fundingagencies.pdf>.)

The first section of this list shows organizations that serve the entire US. The second section is sorted by state to help you find organizations that serve your state and in some cases, specific counties within a state. The last page lists agencies that serve internationally.

Plan some fundraisers and feed your piggy banks to save money for the conference but don't overlook the possibility of getting one or more grants to help cover those expenses. Even if a letter you send doesn't result in financial aid for the conference, it has served another purpose: educating people about CHARGE Syndrome and how it affects an individual and their family!

Now it is your turn. Get organized to apply for one or more grants to attend the conference:

1. Start **NOW!**
2. Read both Wonder Baby Newsletter articles referenced above.
3. Print a copy of the 2nd one, ***Beyond Bake Sales: How to Raise Money So You Can Attend a Family Conference***, to use as a quick reference.
4. Find a sponsor/advocate for your family, as recommended.
5. Do financial homework. Go to **Hotwire, Expedia, Orbitz** and similar sources to get a sound estimate

of your airfare costs. Will an airport shuttle or taxi meet your needs or do you have a specific need to rent a vehicle? If so use these same websites to get estimates for the cost of the rental vehicle and factor this into your transportation costs. Are you a lifetime member of the Foundation? If so, this will reduce conference fees by 10%. **Download** the Excel worksheet from the website to calculate your family's cost to attend the conference. You will need to be able to provide this documentation with your grant requests.

6. **Download** the list of granting agencies from the Foundation's website and read it carefully
 - a. Identify the agencies that you want to contact.
 - b. Go to their websites and read them carefully. Make note of their application requirements. Do you need to submit proof of financial need? Do they require letters of reference from professionals to substantiate your need for conference attendance?
 - c. Assemble the required supporting documentation and have it ready when each agency opens its application period. Do NOT wait until the application period starts to begin this project.
 - d. Mark your calendar with the dates on which you can make application and carefully follow their instructions when you assemble your package for submission. **Don't get your request rejected on a technical or clerical oversight like missing a deadline or not including requested information!**
7. **Download** the sample grant proposal letter from the Foundation's website. Use it as a starting point to create the one you will use for your family's needs.
8. Send this letter to as many source agencies as are available in your city, state, and region. This might result in partial funding from multiple agencies that can add up to 100% funding of your costs.

You'll find a sample letter and financial worksheet and a list of possible funding sources in the complete conference funding guide, available at

<http://www.chargesyndrome.org/wp-content/uploads/2016/11/fundingguide.pdf>

Good luck with your grant applications! See you in Orlando in July.

Sample Letter

Dear _____:

I am writing to ask for your financial assistance in providing travel and conference funding so that I (or my family and I) may attend the **CHARGE Syndrome Foundation Conference, July 27-30, 2017 in Orlando, Florida.**

I (or my son/daughter) was born with CHARGE Syndrome. CHARGE syndrome is a recognizable (genetic) pattern of birth defects, which occurs in about one in every 9,000-10,000 births worldwide. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. In our case, CHARGE has affected me (my child) in the following ways. (Insert a description of the physical, behavioral, educational challenges encountered and what you/your child have done to overcome them). (Hint: try to focus on the positive things & not the negative. You aren't asking for sympathy here; you are asking for funding to help you do one more positive thing related to CHARGE.)

Because the syndrome is so rare, the CHARGE families are often widely dispersed in each state and most only have an opportunity to meet at these conferences. We also have the opportunity to learn from a wide range of professionals from all over the world who are knowledgeable about CHARGE syndrome and its medical, educational, social, and developmental challenges. For most people diagnosed with CHARGE, the conference represents their only opportunity to interact with peers who cope with similar challenges.

Further, this conference is designed to support my (our) entire family. The conference provides "camp" experiences for children with CHARGE and their siblings while their parents attend conference sessions. In addition, "Sibshops" are led by trained counselors who provide a safe and fun environment for siblings, 8 years and older, to meet their peers and share their life experiences and the emotions that stem from having a family member who has the multiple physical and developmental disabilities specific to CHARGE.

The CHARGE Syndrome conference always provides information on cutting edge medical, educational, genetic, and behavioral research and provides an opportunity to speak directly with the researchers as to ways to apply their research specifically to (my/my child's needs). It strengthens our family's bond with the worldwide CHARGE community of individuals and families who strive daily to deal with the challenges that CHARGE Syndrome brings. Spending a weekend with others with CHARGE (or other parents of children and young adults with CHARGE) is invaluable.

Attachment 1

Detailed Costs to Attend the CHARGE Syndrome Conference

SAMPLE –Family of 4

Transportation

Airfare	\$400.00	x	4 (number of people flying)	=	\$1,600.00	
Shuttle/Taxi fare to/from Orlando airport					\$120.00	
Rental Car	\$100-\$200 per day					
Total Transportation Costs						\$1,720.00

Conference Registration*

Adult	325.00	x	2		\$650.00	
Child attending camp	325.00	x	1		\$325.00	
Child not attending camp 12 & younger	225.00	x				
Person with CHARGE	no charge	x	1		\$0.00	
Conference Subtotal						\$975.00
Less 10% Discount for CHARGE Syndrome Foundation Lifetime Members						(97.50)
Total Conference Costs						\$877.50

Hotel

Rosen Shingle Creek	149.00 per night	x	3 Thurs.-Sun.	=	447.00	
Total Hotel Costs						\$447.00
GRAND TOTAL CONFERENCE 2017						\$3,044.50

*Registration fees include: "camp" activities for preteen children; conference sessions for adults and teens over 13; snacks and a light dinner on Thursday; breakfast, lunch, dinner and snacks on Friday and Saturday; and breakfast on Sunday



Our Awareness Items Make Great Holiday Gifts!

We have added new merchandise to the store including CHARGE golf balls, long sleeved t-shirts, and winter hats.

Wear your CHARGE logo items with pride to help create awareness and support the mission of the Foundation.

Spend \$50 and receive a free CHARGE magnet.
U.S. shipping only. Shipping fees apply.



Become A Member

We depend on the commitment of our members to help create a better, more understanding and accepting world for all individuals with CHARGE.

To join or renew, [click here.](#)

Individual	\$30
Lifetime Silver	\$250
Lifetime Gold	\$1,000
Lifetime Platinum	\$5,000
Lifetime Diamond	\$10,000

WEBINAR

WATCH THE CONFERENCE WEBINAR

For Answers To Frequently
Asked Questions
About Conference!



“Charge It for CHARGE” is the Primary Online Fundraising Campaign of the CHARGE Syndrome Foundation.

Your support helps fund research, outreach, and biennial international conferences. You can make a difference!

[SIGN UP HERE](#)