



2014 PMSF Biennial Family Conference
Embracing Today, Empowering Tomorrow!
July 23 – 26, 2014

Please plan to join us for the 2014 PMSF Biennial Family Conference to be held on July 23-26, 2014 at the Caribe Royale in Orlando, Florida. Planning has begun for this exciting conference that you won't want to miss!

PMSF recognizes it may be difficult for some families to afford and attend this conference. We have included information regarding financial assistance resources which may be available to our families, beginning on page 2 and attached a budgeting template (see page 5) that may be helpful for planning your trip.

Here are a few things to know:

Dates: The conference will begin with a New Family Orientation on Wednesday, July 23rd in the afternoon. We will have educational sessions all day Thursday, Friday and Saturday (July 24, 25, 26). There are many great things to do in the Orlando area and you may want to add a few days to your trip to enjoy the attractions.

Conference Registration Fees: The following conference fee schedule is approximate and may change slightly. Please know late fees will apply after June 15, 2014 so be sure to register as soon as registration opens in February of 2014.

Conference Attendees - \$175 per adult

Caregiver/Extended Family - \$65 per adult

Siblings Ages 9 and Up - \$65 per child

Siblings Ages 2 through 8 - \$45 per child

PMS Child and Siblings Under 2 – FREE

Booking Airfare: Orlando International Airport (MCO) is the main airport to use when traveling to Orlando.

Booking Accommodations: Our special group rates for the Caribe Royale are in effect from July 19 – 31, 2014. Our group rates will be offered until June 19, 2014 or until the room block is sold out. As our group rates are available now the Caribe Royale has provided an online group reservation system and a toll free number specifically for the PMSF attendees, you may use the following link or the toll free number to book your accommodations now:

<https://resweb.passkey.com/go/pmsf14> – Toll Free: 888-258-7501

Suite Rates

Queen Double: \$129.00 Standard King: \$129.00 King Deluxe: \$149.00 Villas: \$179.00

Suite rates are based on single/double occupancy. Villa rates are based on up to four adults. Additional adults are \$15.00 each per night. *Please be aware that upon check in a hold will be placed on guest's credit cards or debit cards for charges such as food*



and beverage, gift shop charges, damages to a room, etc. The hold will be \$15 per adult/per day on a credit or debit card. For a cash deposit it is \$50 a day for suites and \$100 for villas.

Dining: The Caribe Royale has several restaurants available onsite and is located within a reasonable driving distance of other dining options. The Caribe Royale suites have a refrigerator, microwave and coffee maker. The villas have fully equipped kitchens as well as laundry facilities in each villa. We will also be offering convenient “grab and go” food and beverages for purchase at the **PMSF Café** that will be located in the convention center (Availability throughout the conference will be based on how many people are using the Café).

Transportation: We are working with Mears Transportation to offer a discount on transportation between the airport and Caribe Royale. Private taxi service can also be used. If you are driving into Orlando, please note that some highways near the Caribe Royale area are toll roads and will require proper coin or cash.

Parking/Rental Cars: Parking at the Caribe Royale is free for PMSF Conference attendees. Rental cars are available at the Orlando International Airport or onsite at the Caribe Royale through Hertz Car Rental.

Sibling Field Trip: Just for the siblings, we have a field trip planned to Islands of Adventure at Universal Studios, Orlando on Thursday, July 24th. Adult chaperones are also needed. The cost is \$75.00 per person and includes round trip transportation from the Caribe Royale to Islands of Adventure, a one day park ticket, and an event t-shirt.

Child Care: Many families travel with a child care provider or family member who helps with child care while parents attend conference sessions. Onsite daytime group child care will be available during session times at the rates below. The staff is qualified to work with children with special needs as well as siblings. Pre-registration will be required. Meals are not included in the child care program, so please plan accordingly.

Wed., 7/23, Afternoon Session 1:30 PM to 5:30 PM - \$45 per child

Thurs., 7/24, Morning Session 8:30 AM to 12:00 PM - \$40 per child

Thurs., 7/24, Afternoon Session 12:00 PM to 5:30 PM - \$55 per child

Full Day - \$75 per child

Thurs., 7/25, Morning Session 8:30 AM to 12:00 PM - \$40 per child

Thurs., 7/25, Afternoon Session 12:00 PM to 5:30 PM - \$55 per child

Full Day - \$75 per child

Thurs., 7/26, Morning Session 8:30 AM to 12:00 PM - \$40 per child

Thurs., 7/26, Afternoon Session 12:00 PM to 5:30 PM - \$55 per child

Full Day - \$75 per child

Times and pricing may change slightly based on participation levels.

Miscellaneous Costs: There are many fun and exciting adventures to be had in Orlando. Don't forget to budget for souvenirs and PMSF onsite store items. Plan now to attend and begin budgeting for the 2014 Conference. A budget worksheet is attached to help you get started. Be sure to check our website often for updated information regarding the 2014 PMSF Biennial Family Conference.

Conference Financial Assistance Resources

Costs associated with traveling to Orlando and attending our conference can seem daunting to some of our families, but it is important for PMS families to come together in one location to share, support, socialize and learn together. Please start planning now in order to attend the conference.

Financial assistance may be available through your own community networks and agencies to help pay for the costs associated with attending the conference. There are state and federal organizations that offer financial assistance to attend conferences. The best way to find an organization to help you is by searching online, networking with friends and neighbors and asking. Help is available and we offer the following as a starting place for your own personal search for funding sources. We ask our families to share any helpful information they uncover by posting on our Family Facebook page (especially International families) and sharing with your Regional Representative so they may disseminate information for your particular area.

1. Local community and service clubs in your particular 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
- Lions
- Kiwanis
- Rotary
- Junior League
- Knights of Columbus
- Masons
- Soroptimist
- Moose Family Fraternities
- Eastern Star

2. If you're a military family, the VFW and American Legion may be able to help.
3. Contact local providers in your area such as ARC, Early Steps Program, Easter Seals or other support groups to which you may belong.
4. Contact your local Parent-to-Parent organization and ask if they know of any support networks that will assist in helping families pay for conference expenses, such as disability related funding.
5. Your local church or temple may offer financial assistance.
6. Your local or state Autism group/organization may offer funds. Additionally, The Autism Society's on-line resource database (www.autismsource.org) allows you to search by location or service type for resources throughout the United States.
7. Look for state or county wide organizations that may assist families with children with disabilities.
8. The United States Department of Health and Human Services Administration on Developmental Disabilities partners with other agencies. Find those in your state.
9. Your local school Exceptional Student Education (ESE) department may know of resources available.
10. The National Dissemination Center for Children with Disabilities (www.NICHCY.org) is a federally funded program that serves as a central source of information on resources available to individuals with disabilities. The website, NICHCY.org, will have state links listing different agencies serving your state.
11. Developmental Disabilities Council (DDC) (<http://www.nacdd.org>) is a planning and advocacy organization committed to community inclusion for people with developmental disabilities. A proposal of one to two pages must be submitted

explaining how our conference promotes the principles of DDC and how it will benefit your family. Using broad terms in your proposal such as inclusion, future planning, family support topics and networking assistance will help your case. Present to the DDC how the information learned at the conference will be disseminated by you to other families in your area, caregivers and educators. Google the phrase Developmental Disabilities Council and the name of your state and call them. DDC has different programs available in different states and may have funding for conference trips.

12. Contact your University Center for Excellence and Protection and Advocacy groups, found on the NICHCY webpage. Often these groups will have a fund to provide family support and education through conferences. These two organizations are sister organizations of the DDC and are required to help families through multiple efforts.
13. Contact your city, state or county's inclusion network which may be found through your State Department of Education.
14. Family Voices (www.familyvoices.org) is a national group that may be able to help you find grant money within your state.
15. Grant money and scholarship funds may be available through various groups, including those below. They may have resources, grants and scholarships:

The M.O.R.G.A.N. Project

Autism Support Network

Family Involvement Fund (by state)

Canyon Rice Hope Scholarships (contact Jenny_L_rice@yahoo.com)

The Different Needz Foundation (www.differentneedzfoundation.org)

Hannah's Helping Hands (<http://hannahandfriends.org>)

The Maggie Welby Foundation (<http://maggiewelby.org>)

Zane's Foundation (www.zanesfoundation.org) - Serves NE Ohio area

The Florida Center for Advocacy, Research and Education – (904-638-6524)

The Independent Order of Odd Fellows (www.ioof.org)

16. If you have a flexible spending account, you may be able to get conference expenses covered.

Using your local contacts and networks you may find an organization willing to help which is not listed here. Please don't be afraid to ask, you may be surprised at what assistance you will receive!

If you have any questions please contact the Foundation's Business Manager Cheryl Herbold at (USA+) (941) 485-8000 or via email at Cheryl.herbold@pmsf.org.

My 2014 Personal Conference Budget Worksheet

Phelan-McDermid Syndrome Foundation - Embracing Today, Empowering Tomorrow: Orlando Florida

BUDGET ITEMS	COST/ESTIMATE (tax, service charges, tips, etc.)	NUMBER OF PEOPLE, DAYS, NIGHTS, TICKETS, ETC.	TOTAL
Airfare		X	=
Lodging		X	=
Dining		X	=
Breakfast		X	=
Lunch		X	=
Dinner		X	=
Transportation		X	=
Shuttle/Taxi		X	=
Car Rental		X	=
Gas		X	=
Parking		X	=
Registration Conference Attendees \$175 per adult		X	=
Registration Caregiver/Extended Family \$65 per adult		X	=
Registration Siblings ages 9 and Up \$65 per child		X	=
Registration Siblings ages 2 - 8 \$45 per child		X	=
Registration PMS Child and siblings under 2 FREE		X	=
Child Care - Wed 7/23 Afternoon Session - \$45 per child		X	=
Child Care - Thurs 7/24 Morning Session only \$40 Afternoon Session only \$55 Full Day \$75		X	=
Child Care - Thurs 7/25 Morning Session only \$40 Afternoon Session only \$55 Full Day \$75		X	=
Child Care - Thurs 7/26 Morning Session only \$40 Afternoon Session only \$55 Full Day \$75		X	=
Sibling Field Trip to Islands of Adventure Universal \$75 per person		X	=
Miscellaneous Costs		X	=

Registration, child care & field trip fees are estimated and may change slightly. Late fees will apply for registrations after June 15, 2014.

Choose Your Personal Savings Plan

Option 1: Monthly Savings Plan

Total amount divided by number of months = amount to set aside each month from now until the conference. (We suggest making June, 2014 your last savings month to allow for early registration and airfare rates.)

Option 2: Bi-Weekly Savings Plan

Total amount divided by number of bi-weekly pay periods = amount to set aside every two weeks from now until June, 2014.

Option 3: Weekly Savings Plan Total amount divided by number of weeks before early registration deadline = amount to set aside every week from now until June 2014.