

2018 SBP Rare Disease Day Symposium & CDG Family Conference February 23-25, 2018 San Diego, California

EVENT INFORMATION – SCIENTIFIC ATTENDEES

We proudly invite you to the **2018 SBP Rare Disease Day Symposium & CDG Family Conference**, February 23-25, 2018 in San Diego, CA. This year's event is organized by [CDG CARE](#) and [NGLY1.org](#) in partnership with [Sanford Burnham Prebys \(SBP\) Medical Discovery Institute](#).

To participate, please see the attached details and go online to register at sbpdiscovery.org/rarediseaseday or our [Eventbrite registration page](#), as space is limited! If you prefer to pay by check, instructions are included below, and registration forms are at the end of this document.

Scientific Registration closes January 9, 2018

ABOUT THE CONFERENCE

Scientific topics will include:

1. PMM2-CDG: Overview, Models and Therapies
2. Other Glycosylation Disorders: Models and Therapies
3. NGLY1: A Disorder of Glycosylation

Family topics will include:

1. Education on the science behind this class of disorders
2. Resources available for patients and families
3. Interventional and therapeutic approaches

Scientific and family meetings will be bridged by **three interactive events**:

- A **poster session** on Friday evening where junior investigators and postdocs present emerging science alongside patient and advocate presenters.
- SBP's innovative **doctor-is-In session**, where physicians and scientists meet with small groups of like-minded family members in a round-robin format, on Saturday afternoon.
- **Family/Scientist Networking** time on Saturday evening.

To learn more about the symposium and family conference, including confirmed speakers and topics, [click here to view the preliminary agenda](#). Please note that speakers and topics are subject to change. **To facilitate communication between the scientific and family communities, all participants are encouraged to attend the full symposium.**



EVENT OVERVIEW

Friday, February 23, 2018

9:00am-5:00pm - SBP Scientific Session

5:00pm-7:00pm - Poster Session

Saturday, February 24, 2018

9:00am-12:00pm - SBP Scientific Session

1:00pm-4:00pm - Doctor-Is-In Session

4:00pm-7:00pm - Family/Scientist Networking

Sunday, February 25, 2018

8:00am-5:00pm - CDG Family Conference

REGISTRATION PRICING

The **2018 SBP Rare Disease Day Symposium & CDG Family Conference** is made possible by donations, corporate and industry sponsorships, volunteers, and nominal participant registration fees. These fees support material costs, meeting space, catering, and equipment required for the conference.

The registration fee for the 3-day symposium includes access to all Conference sessions, daycare service, lunch, and light refreshments during conference break times.

CDG parents and caregivers can **choose to attend the full conference, or purchase single-day tickets**. Prices are per person. CDG patients and siblings are free.

General Admission
\$150

Academic/Non-Profit
\$120

CDG Parents/Caregivers
\$40/day or \$100 for the full meeting

CDG Patients/Siblings
Free

PAYMENT

Online

Online payment can be made via credit card (Visa, Mastercard, Discover, AMEX) on our [Eventbrite registration page](#) (click the green Tickets button). Payment will be collected at checkout. Patient/sibling registration is free.

By Check

Detailed instructions for paying by check can be found in this document on [Page 5](#).

What's the refund policy?

The cancellation deadline is **January 23, 2018**. Please note that all registration cancellations will be charged a \$30 cancellation fee. To request a cancellation, send a written notification by email to azimmon@sbpdiscovery.org, and a member of the event team will follow up with you directly.

No refunds will be issued for requests received after the cancellation deadline.



EVENT HOTEL AND ACCOMODATIONS

The **2018 SBP Rare Disease Day Symposium & CDG Family Conference** hotel and meeting venue is:



The Dana Hotel on Mission Bay

1710 W Mission Bay Drive
San Diego, CA 92109
(800) 445-3339
www.thedana.com

The Dana Hotel on Mission Bay is located in one of San Diego's favorite family vacation areas, minutes away from local attractions. A room block for the 2018 event is available at The Dana on Mission Bay at the discounted rate of **\$135/night** for a standard room or **\$175/night** for a bay view upgrade. This rate is good for up to three days before and after the symposium, and includes free parking and free wi-fi.

To reserve your room, [click here to book online](#). The group code for online booking is **CDGCONFRNC**. You can also call **(800) 445-3339** and identify yourself as part of the **CDG Annual Conference**.

The hotel's reservation deadline is January 23, 2018.

An advance deposit or credit card guarantee for the first night's room and tax is required. Space is limited – early reservations are recommended.

FAQs

Are children able to attend the symposium?

All ages are encouraged to attend the event.

What childcare/daycare services are available?

The 2018 SBP Rare Disease Day Symposium & CDG Family Conference will offer a Therapeutic Daycare Program* for both children and young adults affected by CDG and their siblings. The daycare program is included in the registration fee, but space is limited, so advance registration is required.

Highlights of the Daycare Program will include: sensory and educational benefits provided through a music, art and storytelling program; physical interaction and exploration of animals through a wildlife experience; a full-day of occupational therapy and fun through the "Movement, Muscles and Messes" program provided by a local University Pediatric OT Program; and a variety of "carnival" booth entertaining exhibits offering face painting, photo booth opportunities and additional fun games, free exploration and movie presentations.

**Pre-registration for the Daycare Program must be completed by registering each child using the CDG Patient/Sibling ticket type (Enroll in onsite childcare program; Choose Yes). Approximately 3 months prior to the Conference, a staff member will*



contact all families who have pre-registered to gather additional information and provide families with the hours, policies and procedures of the Daycare.

What is the Doctor-Is-In Session?

Now in its ninth year, the SBP Rare Disease Day Symposium's Doctor-Is-In-Session brings together medical researchers, clinicians, advocates, patients and their families for an afternoon of hands-on collaboration in a small-group, round-robin format. Families and professionals choosing to participate in this innovative information-sharing session will be contacted by event staff with more information. To pre-register, please be sure to select the "Doctor-Is-In Session" on your order form.

How do I participate in the Poster Session?

New in 2018, a poster session the evening of **Friday, February 23, 2018** will provide a unique opportunity for junior investigators and postdocs to present emerging science on Congenital Disorders of Glycosylation and Deglycosylation *alongside patient and advocate presenters*.

Poster presenters must submit an abstract no later than Friday, January 19, 2018. Abstracts are limited to 250 words. [Please click here to download a Poster Session registration form](#). In addition to Friday's event, selected participants will be chosen by the selection committee to give a 10-minute oral presentation to symposium attendees on **Saturday, February 24, 2018**.

The Poster Session will begin at 5:00pm on February 23, 2018 at The Dana on Mission Bay. Admission to the Poster Session is included with your registration. **Please note that registration to the full meeting on February 23 is required to attend this event.** Light refreshments will be provided.

What are my transportation/parking options for getting to and from the event?

The Dana on Mission Bay is located 7 miles from the San Diego International Airport. Please note that public transportation in San Diego is limited and the hotel does not have a dedicated airport shuttle.

A one-way traditional taxi fare is approximately \$40 with tip. Ride-sharing services such as Lyft (\$13-\$30 one-way)* or Uber (\$13-52 one-way)* are widely used in the San Diego area. Renting a car is often the most economical option for a family visiting San Diego. The hotel does offer a free shuttle to nearby Sea World and Belmont Park, and parking at The Dana on Mission Bay is free.

*fare depends on class of service (basic to premium)

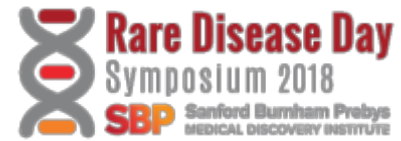
What meals are included with my registration fee?

Your registration fee includes lunch and light refreshments during session breaks, as well as admission to the Poster Session on Friday, February 23 and Family/Scientist Networking time on Saturday, February 24 (per-day tickets include events on the date of purchase).

Breakfasts and dinners are not included. However, the hotel does have a dining establishment onsite and is offering a discounted all-inclusive buffet breakfast rate of \$15.00 per adult/\$7.50 per child for Conference attendees (Kids under 5 eat free). These vouchers may be purchased upon arrival at the hotel.



NGLY1.org



There is a General Store within walking distance where you can purchase food items and toiletries but please note that there are limited dining options within walking distance. More information can be requested from the hotel at check-in.

PAYING BY CHECK

Please fill out **one registration form for each attendee** and return the forms to **Amy Zimmon** via email at azimmon@sbpdiscovery.org or fax to 858-795-5381.

Payment is required within 14 days. **Make your check payable to NGLY1.org** and mail it directly to the address below within 5 days of submitting your registration. **Amy Zimmon** at SBP will collect registration fees and forward them to NGLY1.org for processing. Registrations not paid by **January 23, 2018** will be canceled. You will receive an email confirmation from a member of the registration team once your check is received and your registration is complete.

Mailing Address:

Sanford Burnham Prebys Medical Discovery Institute
Attention: Amy Zimmon, Building 12
10901 North Torrey Pines Road
La Jolla, CA 92037

What's the refund policy?

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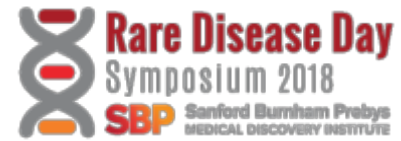
CONTACT INFORMATION

Questions regarding the **2018 SBP Rare Disease Day Symposium & CDG Family Conference** may be addressed to the following contacts:

SBP: Amy Zimmon, azimmon@sbpdiscovery.org;

CDG CARE: Andrea Berarducci, conference@cdgcare.com;

NGLY1.org: Carrie Ostrea, carrie@ngly1.org



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Scientific Registration Form

Please fill out one registration form per person. Be sure to indicate which sessions you plan to attend. Meal counts will be generated from your feedback.

Registrant Information

First Name: _____
Last Name: _____
Email Address: _____

3-Day Inclusive Registration

Quantity	Fee	Type	Description
_____	\$150.00 USD	General Admission	The general admission registration fee for the 3-day symposium includes access to all Conference sessions, daycare service, lunch, and light refreshments during conference break times. Please see below for discounted admission for non-profit, academic, and CDG family attendees.
_____	\$120.00 USD	Nonprofit/Academic Admission	This ticket provides the same access as the General Admission category, with a discounted fee for academic and non-profit organizations.

Per-Day Pricing

Total: _____

I plan to attend the following event sessions:

Attending	Session Title
_____	Friday February 23, 2018, 9:00am-5:00pm (SBP Scientific Session)
_____	Friday February 23, 2018, 5:00pm-7:00pm (Poster Session)
_____	Saturday, February 24, 2018, 9:00am-12:00pm (SBP Scientific Session)
_____	Saturday, February 24, 2018, 1:00pm-4:00pm (Doctor-Is-In Session)
_____	Saturday, February 24, 2018, 4:00pm-7:00pm (Family/Scientist Networking)
_____	Sunday, February 25, 2018, 8:00am-5:00pm (CDG Family Conference)

Information/Photo Release and Policy

I grant to Sanford Burnham Prebys Medical Discovery Institute (SBP), CDG CARE, and NGLY1.org, as well as their representatives and employees, the right to take photographs of me and my property in connection with the 2018 SBP Rare Disease Day Symposium & CDG Family Conference February 23-25, 2018 in San Diego, CA. I authorize SBP, CDG CARE, and NGLY1.org, as well as their assigns and transferees, to copyright, use and publish the same in print and/or electronically. I agree that such photographs of me may be published with or without my name and for any lawful purpose, including for example such purposes as publicity, illustration, advertising, and Web content. I have read and understand the above.

I agree to the above waiver

_____ Yes
_____ No

Signature _____
Date _____