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**The 10th International CHARGE Syndrome Conference
for Families and Professionals**

[Friday – Sunday, July 29-31, 2011]

And

2nd Professional Day

[Thursday, July 28, 2011]

at the Rosen Shingle Creek Resort, Orlando, FL

**CALL FOR PLATFORM PRESENTATIONS,
POSTER PRESENTATIONS, EXHIBITS,
DEMONSTRATIONS,
AND ON-SITE RESEARCH PROJECTS**

Deadline for Submission: November 1, 2010

Marilyn Ogan, 2011 Program Chair

**The 10th International CHARGE Syndrome Conference
for Families and Professional Day**

The primary purposes of the CHARGE Syndrome Conferences have always been 1) to provide information to individuals with CHARGE and their parents and families and to professionals and 2) to provide an environment in which families can communicate and establish relationships with each other and with the professionals. The presenters at these conferences are selected using two criteria: 1) the relevance of the information they have to present and 2) their ability to present the information effectively to parents and, more recently, to adults with CHARGE. In 2011, we will continue the tradition of platform presentations and poster sessions that we have had in the past. Several groups have conducted on-site research at Conference that included data collection (questionnaires, physical examinations, and blood samples) with prior approval by the Foundation. We also encourage exhibits and demonstrations by institutions, organizations and individuals.

This is the call for proposals for several types of presentations for the Conference for Families and Professionals. There are three categories of presentations: 1) 50-minute platform presentations that will be presented at break-out sessions on Friday and Saturday; 2) poster presentations, demonstrations, and exhibits that will

be presented during a 2+hour plus multipurpose session on Friday afternoon; and 3) exhibits and on-site research projects that may run the length of the Conference.

At the last conference, presentations were grouped into the following categories based on the needs of families and on the proposals received:

ED = Education or development **GI** = General interest **NF** = New family information
FS = Family support **MG** = Medical or genetic **TA** = Transition-to-adulthood

There are likely to be new categories in 2011. In particular, there will be a place for **Kabuki syndrome**. In 2009, the following professions and participant groups were represented:

-Audiologist	-Individual with CHARGE	-Physician/surgeon
-Deaf-blind specialist	-Medical geneticist	-Psychologist
-Deaf-educator	-Occupational therapist	-Special educator
-Family specialist	-Parent of child with CHARGE	-Speech-language pathologist
-Genetic counselor	-Physical therapist	

50-Minute Platform Presentations.

Throughout most of the conference, there will be either three or four 50-minute breakout sessions running concurrently. The platform presentations at these sessions will be presented to large groups – primarily composed of parents. Because of time and space constraints, only a limited number of proposals for platform presentations will be accepted. Proposals will be given priority that meet needs in specific topic areas and that are family-friendly. There is the expectation that platform presenters will be available during the conference and at the Multi-Purpose Session to talk with conference participants. Since the number of time slots for platform presentations is limited, please consider presenting the information as a poster as an alternative.

Multi-Purpose Session. The latter part of Friday afternoon will be devoted to a single 2+ hour session that will include the following:

Poster Presentations: Poster presentations are intended to convey information to participants in a personal form that permits interaction with participants. Posters are particularly appropriate for topics that may not have general interest but target specific groups of participants. Each poster presenter will be provided with a 4'x8' display sheet of cardboard and tape to attach the poster. It is our hope that posters will be presented first at the Professional Conference and then at the Multi-Purpose Session at the Conference for Families and Professionals.

Exhibits: Exhibits are non-commercial displays by institutions, organizations, groups, or individuals during the Multi-Purpose Session

Demonstrations: Some members have expressed interest in presenting demonstrations of procedures and activities. This is a new category for this conference. Proposals should include a description of requirements for space and furniture.

On-Site Research Projects: Institutions and organizations with authorization to conduct human subject's research may request to conduct research throughout the conference

The 2nd Professional Day at the 10th International CHARGE Syndrome Conference

At previous conferences, professionals who were scheduled to present were invited to meet informally on Thursday afternoon before the main conference. The professionals introduced themselves to each other and briefly described their involvement with CHARGE: research, therapy, deaf-blind services, medical and surgical treatment, genetic services, educational and vocational services etc. The issues with CHARGE are so broad in scope and involve so many disciplines that the professionals at these meetings find themselves interacting with their peers in a very non-competitive atmosphere. Professionals are often able to identify professionals in other disciplines who have been addressing similar issues with entirely different approaches. The general impression of those who have participated in these informal meetings is that they are refreshing, informative, and a great means of networking.

There were three reasons for creating a formal CHARGE Conference Professional Day. In the 1990's, CHARGE was seen as a rare and little known disorder. More recently, it has gained prominence both because of the identification of relation between micro-deletions in the CHD7 gene and CHARGE and because it is now recognized as one of the leading known genetic causes of deaf-blindness. Second, at each conference the number of professionals attending the informal Thursday meetings has increased. In 2007, there were over 80 individuals in attendance, and the process of introductions and group interactions reached its upper limit. A more formal structure was needed. And third, this conference will be only the second forum in which the *primary* purpose is for professionals involved in CHARGE to present scholarly, scientific, medical, and educational work to their peers. You are invited to submit work presentations and posters that are intended for a professional audience and also for the Conference for Families and Professionals.

As a side note, a number of parents expressed interest in attending the Professional Day. The Foundation Board decided that parents will be invited to attend the Professional Day, but there would be no expectation that the presentations would be geared toward parents. Additionally, it was determined that it would be inappropriate for parents to raise questions about their children as a part of the discussion at the Professional Day. The primary purpose for the Professional Day is to provide a venue for peer interaction among professionals.

The format of the Professional Day is being developed at this time and will depend on the number and types of proposals received. There will be 1) platform presentations (probably ranging in length from 15 to 30 minutes), 2) posters presented in the afternoon of the professional conference, and 3) discussion groups based on specific interest areas.

There will be a separate registration fee of \$90 for the Professional Day for all who attend. It will be a full-day conference. The fee will cover 1) the cost of a notebook with information about presenters and each presentation, 2) snacks and beverages at breaks, and 3) a luncheon. As in past years, the opening reception for the family Conference will be Thursday evening following the Professional Day.

Continuing education units *may* be available for attendance during the Professional Day. If you wish to be able to obtain continuing education credit, please notify us and indicate your credentialing organization so we can determine if offering CEUs and/or Professional Development Points is feasible. The Foundation is currently developing a Certificate for Professional attendees.

SPEAKER REIMBURSEMENT

Principal speakers are requested to seek funding from their employers or funding organization. If the principal speakers are in need of additional funding, they may request assistance from the Foundation and will be considered for assistance if funds are available. Other presenters at the full conference or at the professional conference will not be eligible for reimbursement. Absent good cause, the Foundation will not waive registration fees or pay expenses at the CHARGE Conference for speakers.

PROPOSAL SUBMISSION FORM

Please complete the attached submission form and email it to the Program Committee Chair Marilyn Ogan (marilyn@chargesyndrome.org). If you have questions about the program, email them to Marilyn Ogan as well. You will be notified of the Program Committee's decision in January 2011.

If there are other professionals that you think would be interested in this conference, please share this information with them.

Marilyn Ogan, 2011 Program Chair **Janet Murray, 2011 Conference Chair**
The CHARGE Syndrome Foundation, Inc. 141 Middle Neck Rd. Sands Point, NY 11050

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