

The 9th International CHARGE Syndrome Conference

Friday – Sunday, July 24-26, 2009

and

The 1st International CHARGE Syndrome Conference for Professionals

Thursday, July 23, 2009

both at the Indian Lakes Resort, Bloomingdale, IL



AN INVITATION

TO ATTEND THE CONFERENCE FOR PROFESSIONALS

AND A

SOLICITATION FOR

PRESENTATION PROPOSALS

FOR BOTH CONFERENCES

James W. Thelin, 2009 Program Chair

This is a solicitation for *informal* proposals for **platform presentations, posters, demonstrations, exhibits, and on-site research projects** for the CHARGE Syndrome Conference *and* for the one-day CHARGE Syndrome Conference for Professionals that will precede the full conference. At the last conference, presentations were grouped into the following categories based on the proposals that were 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 2009. In particular, there will be a place for **Kabuki syndrome**. In 2007, the following professions and participant groups were represented:

-Audiologist

-Medical geneticist

-Physician/surgeon

-Deaf-blind specialist

-Individual with CHARGE

-Psychologist

-Deaf-educator

-Occupational therapist

-Special educator

-Family specialist

-Parent of child with CHARGE

-Speech-language pathologist

-Genetic counselor

-Physical therapist

The purpose of this solicitation is to identify individuals who are interested in presenting at the conferences. It will give the program committee an idea of the areas in which work is being done. If you respond to this solicitation, you will be sent a request for formal proposal(s).

The 9th International CHARGE Syndrome Conference

The primary purposes of the CHARGE Syndrome Conferences have always been 1) to provide information to individuals with CHARGE and their parents 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 2009, we will continue the tradition of platform presentations and poster sessions that we have had in the past. Two groups conducted on-site research at the last Conference. Alt: Data collection for research (including blood drawing, questionnaires and examinations) has been done at previous conferences with prior approval by the Foundation. We also encourage exhibits and demonstrations by organizations and individuals.



The 1st International CHARGE Syndrome Conference for Professionals

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 for Professionals. 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 CHD7 as a major gene and because it is now recognized as a leading cause 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 is needed. And third, this conference will be the first 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. You may do this for the Conference for Professionals in addition to any proposals you have for the general conference.

As a side note, a number of parents expressed interest in attending the Conference for Professionals. The Foundation Board decided that parents will be invited to attend the Conference for Professionals, 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 Conference for Professionals. The primary purpose for the Conference is to provide a venue for peer interaction among professionals.

The format of the Conference for Professionals 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 during a special session, and 3) discussion groups based on specific interest areas.

There will be a separate registration fee of \$90 for the Conference for Professionals 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 Conference.

Continuing education units *may* be available for attendance the Conference for Professionals. 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 is feasible.

INFORMATION FOR THE PROGRAM COMMITTEE

Please see the attached sheets concerning attendance as a participant at the Conference for Professionals and informal proposals to present at either or both conferences. *The request is made that these forms be returned quickly to the Program Committee, preferably by email.*

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

The 1st International CHARGE Syndrome Conference for Professionals

Thursday, July 23, 2009
Indian Lakes Resort, Bloomingdale, IL

INTEREST IN ATTENDING
THE CONFERENCE FOR PROFESSIONALS

October 3, 2008

I am interested in attending the CHARGE Conference for professionals as a participant and not as a presenter.

Name:

Mailing Address:

Email address:

Telephone:

_____ I am a parent.

_____ I am a professional. Profession:

Continuing Education Units (CEUs)

_____ I am interested in receiving CEUs (if possible)

Name of credentialing organization:

Topics in which I have particular interest:

Presenters I wish to recommend:

Please send this form to:

James W. Thelin, Program Chair Home address: 2209 Delta Way,
2009 CHARGE Conference Knoxville, TN 37919-9108
Email: jthelin@utk.edu Home TEL: 865-539-2179

PLEASE RETURN THIS FORM AS SOON AS POSSIBLE.

If there are others that you think would be interested in this conference, please share this form with them.

The 1st International CHARGE Syndrome Conference for Professionals
Thursday, July 23, 2009
Indian Lakes Resort, Bloomingdale, IL

Informal Proposal for Presentation at the
CHARGE Syndrome Conference for Professionals

Name:

Mailing Address:

Telephone:

Email address:

:

Title and institutional or professional affiliation:

Preliminary title and brief description of presentation:

Co-presenters:

Preferred type of presentation:

Platform presentation (Time required: _____) Exhibit

Poster presentation Demonstration

Continuing Education Units (CEUs): I am interested in receiving CEUs (if possible)

Name of credentialing organization:

Other topic areas in which I am interested hearing presentations:

Please send this form to:

James W. Thelin, Program Chair Home address: 2209 Delta Way,
2009 CHARGE Conference Knoxville, TN 37919-9108

Email: jthelin@utk.edu Home TEL: 865-539-2179

FAX: 865-974-1539

PLEASE RETURN THIS FORM AS SOON AS POSSIBLE, preferably by email.

When this form is received by the Program Committee, a request for formal proposal will be sent to you with submission deadlines and information for presenters.

The 9th International CHARGE Syndrome Conference

Friday - Sunday, July 24-26, 2009
Indian Lakes Resort, Bloomingdale, IL

Informal Proposal for Presentation at the
CHARGE Syndrome Conference

Name:

Mailing Address:

Telephone:

Email address:

Title and institutional or professional affiliation:

Preliminary title and brief description of presentation:

Co-presenters:

Preferred type of presentation:

Platform presentation (Time required: _____) Exhibit

Poster presentation Demonstration

Continuing Education Units (CEUs): I am interested in receiving CEUs (if possible)

Name of credentialing organization:

Other topic areas in which I am interested hearing presentations:

Please send this form to:

James W. Thelin, Program Chair Home address: 2209 Delta Way,
2009 CHARGE Conference Knoxville, TN 37919-9108

Email: jthelin@utk.edu Home TEL: 865-539-2179

FAX: 865-974-1539

PLEASE RETURN THIS FORM AS SOON AS POSSIBLE, preferably by email.

When this form is received by the Program Committee, a request for formal proposal will be sent to you with submission deadlines and information for presenters.

The 9th International CHARGE Syndrome Conference

Friday – Sunday, July 24-26, 2009

and/or

The First CHARGE Syndrome Conference for Professionals

Thursday, July 23, 2009

Indian Lakes Resort, Bloomingdale, IL

Suggestions for Presenters or Topics
for Both Conferences

Please use a separate sheet for each suggestion.

Individual making the suggestion:

Mailing Address:

Telephone:

Email address:

PRESENTATION TOPIC:

If you have a specific presenter in mind please provide whatever contact information you have:

Name:

Mailing Address:

Telephone:

Email address:

Please send this form to:

James W. Thelin, Program Chair Home address: 2209 Delta Way,

2009 CHARGE Conference Knoxville, TN 37919-9108

Email: jthelin@utk.edu Home TEL: 865-539-2179

FAX: 865-974-1539

PLEASE RETURN THIS FORM AS SOON AS POSSIBLE, preferably by email.

When your suggestion is considered by the Program Committee, you or the person you have suggested may be contacted for additional information.