#ChordomaCommunity

@ChordomaFDN

Follow the conversation and tweet with us!
Our Mission

- To improve the lives of those affected by chordoma, and
- To lead the search for a cure
Lightning history:
CF through the years
2007

Dining Room Table Board Meeting
Focusing on Basic Science First

• First Research Conference in 2007 started a lasting dialog and collaborations among less than 50 researchers. Today, hundreds globally and 115 here in Boston.

• We had no cell lines, no animal models and no clinical trials. Now we have all three.

• We knew little about the biology of the disease, we now have potent information about the genetics and biology of the disease.

• We focused first on the basic science before we could focus on serving patients.
2008 First CCC – Bethesda, MD
Dual focus – Science and Patients

• Since that first meeting in 2008 we have held 11 total patient gatherings,
  – Three in Europe: The Netherlands, Germany and Italy
  – Three regional medical center partner meetings in LA, NY and this year in Rochester, Minnesota.
  – Begun clinical trials
  – Created a Doctor Directory
  – Supported the work to create expert consensus on treatment
  – Created a Peer Support Program
  – Started a Patient Services Program and hired a Patient Service Manager
2015 Expert Recommendations
2015 Milan Community Conference
We are here to help you

• Learn about chordoma
• Get the best care possible
• Overcome obstacles
• Get emotional support
• Be part of the solution
A few reminders:

• Learn medical terminology: Glossary of terms in Expert Recommendations booklet
• Please, no “curbside consults”
• Ask the Experts: Make questions “short and sweet” to maximize the number of questions
• Meet new people, make lasting relationships
Today We Hope You Will:

1. Learn
2. Connect
3. Take Action
Follow the conversation and tweet with us!

#ChordomaCommunity

@ChordomaFDN
What’s happening in Patient Services?

- Educational Resources
- Community Conferences
- Patient Navigation Service
- Community Advisory Board
- Doctor Directory
- Peer Connect
Educational Resources

- Series of guides based on stage of your journey
- Treatment specific pamphlets
- Updated Expert Recommendations
- Translations
- Available for download or in print
Patient Services

- Community Conferences
- Educational Resources
- Patient Navigation Service
- Community Advisory Board
- Doctor Directory
- Peer Connect
**Added 50 doctors to the Doctor Directory since January of this year**

**New design**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michael Chicoine, MD</td>
<td>Skull Base Surgeon at Washington University in St. Louis</td>
</tr>
<tr>
<td>Dean Chou, MD</td>
<td>Spine Surgeon at University of California San Francisco</td>
</tr>
<tr>
<td>Edwin Choy, MD, PhD</td>
<td>Medical Oncologist at Massachusetts General Hospital</td>
</tr>
<tr>
<td>Rashmi Chugh, MD</td>
<td>Medical Oncologist at University of Michigan</td>
</tr>
<tr>
<td>Gregory Cote, MD, PhD</td>
<td>Medical Oncologist at Massachusetts General Hospital</td>
</tr>
<tr>
<td>William Couldwell, MD PhD</td>
<td>Skull Base Surgeon at University of Utah School of Medicine</td>
</tr>
</tbody>
</table>

**Additional contact information**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
<th>Clinical Phone</th>
<th>Email</th>
<th>Address</th>
<th>Treats</th>
<th>Provides Remote Consults</th>
<th>Patient Point of Contact</th>
<th>Links</th>
</tr>
</thead>
<tbody>
<tr>
<td>Silvia Stacchiotti, MD</td>
<td>Medical Oncologist at Fondazione IRCCS Istituto Nazionale dei Tumori</td>
<td>+39 022 390 2803</td>
<td><a href="mailto:silvia.stacchiotti@istitutotumori.mi.it">silvia.stacchiotti@istitutotumori.mi.it</a></td>
<td>Fondazione IRCCS Istituto Nazionale dei Tumori, via venezian 1 Milano, 20133 Italy</td>
<td>Adults</td>
<td>Yes</td>
<td>+39 022 390 2803</td>
<td>Publications</td>
</tr>
</tbody>
</table>
Patient Services

- Community Conferences
- Educational Resources
- Doctor Directory
- Peer Connect
- Patient Navigation Service
- Community Advisory Board
Peer Guide training – Boston 2016
Patient Services

- Community Conferences
- Educational Resources
- Doctor Directory
- Peer Connect
- Patient Navigation Service
- Community Advisory Board
Patient Services

- Community Conferences
- Educational Resources
- Patient Navigation Service
- Community Advisory Board
- Doctor Directory
- Peer Connect
Patients and families served April 2015 – May 2016
Patient Services

- Community Conferences
- Educational Resources
- Doctor Directory
- Peer Connect
- Patient Navigation Service
- Community Advisory Board
THANK YOU TO THE CONFERENCE SPONSORS

Bristol-Myers Squibb

UPMC LIFE CHANGING MEDICINE

PACIFIC NEUROSCIENCE INSTITUTE™

Stephan L. Harris Center for Chordoma Care

NF Institute of Cancer Epidemiology and Genetics

UFHealth PROTON THERAPY INSTITUTE

Individual sponsors
Gene and Sue Brenneman  Jeanne and Robert Dobos
Su Chen  Cindy and Scott Frodle
Peter Davidoff  Heather Lee and Steve Straus
Kris Stahl
#ChordomaCommunity

@ChordomaFDN

Follow the conversation and tweet with us!