

## 2015 MDF Annual Conference



Sept. 18 - 19, 2015 Washington, DC

### Community-Led Track

# DM2: Finding the Right Doctors & Self-Advocacy

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Tina Pinsonneault

# Tom McPeek





# a Pinsonneault





# Rob Besecker





# The Diagnostic Odyssey...



nia, light

#### In my 40s

Began experiencing a lot of leg pain

#### 2008

• DM2 diagnosis

#### 2008-2012

 Did a lot of research to locate a neurologist in Columbus

#### 2013

Assembled a good team of doctors

#### 2015

• Still looking an anesthesi





1999

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 Bone spurs, tired & weary legs 2000-2003

 No longer could jump, back problems, hip flexors gave out 2003

• Hypersomnia

2007

• Fell off ladder, weak neck muscles

2008

 Third pregnancy intensified symptoms, diagnosed with DM2 2008-2013

• Doctor visits, drugs, & cane

2014

• Dr. C Thorappe







	2000	2001	2003	2004	2006	2011
Family ry,	Diagnosed with atrial fibrillation	Dizzy spells & doctor visits	Hypertrophic cadiomyopathy, initial ICD surgery	•Brother died	• Diagnosed with DM2	•Majo event cardia surge







## Lessons Learned...









#### DYSTROPHY COMMUNITY FORUM

Bringing the community of DM families together

**SUMMARY** MY PAGE **MEMBERS FORUM GROUPS EVENTS BLOGS PHOTOS VIDEOS** INVITE MANAGE Members must be approved DM2 Support Group is accepting new members. If you would like to join, click here to request access from the Group Creator. All Groups My Groups → Join DM2 Support Group Options Options Sign Out **DM2 Support Group**  Inbox Created by John Brekka 🔀 Send Message 👗 View Groups Alerts Friends - Invite **INFORMATION o**<sup>o</sup> Settings This page is for issues related to DM2 only and membership is restricted to DM2 diagnosed patients only. CONNECT MEMBERS (91) Members: 91 Latest Activity: Feb 24 You Tube Linked in. twitter facebook Edit **GROUPS** 



# Self-Advocacy...

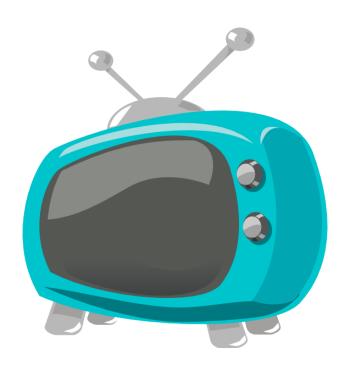
Take your research with you to see doctors

Make at least one trip to see one of the top 5 DM researchers

Get second opinions

Talk with others with DM2





# Self-Advocacy...

Open communication with your physicians
Become familiar with DM2 and the symptoms
Take an active role in your lifestyle development



# Self-Advocacy...

You will cycle through different emotions

Find online groups for support: MDF Community Forum, Facebook

Research – books, medical publications

Ask a lot of questions



### Continue the Conversation

#### MDF DM2 Group on Facebook

Face-to-Face MDF support groups throughout U.S., Ottawa, and Switzerland: <a href="http://myotonic.org/find-support">http://myotonic.org/find-support</a>



