



the  
christopher  
project

Sarah Howe, Study Coordinator  
Myotonic Dystrophy Foundation Annual Conference  
Saturday, September 13, 2014

# The Project

- Surveys patients and families living with myotonic dystrophy
- Collaborative partnership
- Complements existing research
- Learning directly from patients and families

**YOU are the experts!**

Partners:



MYOTONIC  
DYSTROPHY  
FOUNDATION

 Muscular  
Dystrophy Canada

  
Fighting Muscle Disease

  
The Marigold Foundation  
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GRIMN

- Patient Survey—summer 2014
- Family Member/Caregiver Survey—autumn 2014
- Interviews & Focus Groups—2014/2015
- Reporting—2015

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## Summer 2014

- What are the biggest challenges?
- Where have people met with success?
- How can we do better?

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|        | Distributed | Completed |
|--------|-------------|-----------|
| Canada | 696         | 224       |
| USA    | 3,168       | 877       |
| TOTAL  | 3,864       | 1,101     |

**28% Response Rate**

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# Who is Christopher?



I started having problems when I was about 20 years old. My doctor sent me to different specialists but no one knew what was going on. It was only when my sister had a baby with myotonic dystrophy that we figured it out. I wish we had known sooner.

I am **Christopher**.

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# Who is Christopher?



My wife has myotonic dystrophy and so do our two kids. I try to take care of everyone but it's not getting any easier. It's very hard to manage our life and all the things we need to do to stay on top of this disease. I wish we knew more.

I am **Christopher**.

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# Who is Christopher?



I love my job but it's getting harder to do. My fingers don't work like they used to and I'm so tired. My boss has noticed but I don't know how to talk to him about it. What should I do?

I am **Christopher**.

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# Take the Survey

Online: [www.christopherproject.org](http://www.christopherproject.org)

-or-

Contact: Sarah Howe, Study Coordinator

Toll Free: [1-855-506-4646](tel:1-855-506-4646)

Email: [support@christopherproject.org](mailto:support@christopherproject.org)

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Together  
we can make  
a difference

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Thank  
you!

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