

A mitoPodCast Interview with Blaine Penny



MEET BLAINE PENNY

Blaine is the co-founder and CEO of the MitoCanada Foundation. He is a past President of MitoCanada, having chaired the board from its founding in 2009 until 2015. Blaine coordinates many advocacy initiatives and support programs for patients coping with mitochondrial diseases.

MITOCANADA'S ORIGINS

After his son Evan was diagnosed with mitochondrial disease, Blaine found there was no organization in Canada that provided support for families or raised awareness for mitochondrial disease. After meeting other Canadian families with diagnosed loved ones, it was decided that one needed to be created in Canada that would advocate for patients and support research.



NEXT STEPS

Blaine and MitoCanada will continue their efforts to develop a mitochondrial disease patient registry as no formal one currently exists in Canada. In addition, they will advocate for public and private coverage of medically necessary foods and vitamin supplements to help patients and their families manage the high costs. During the COVID-19 pandemic, MitoCanada will also continue to support patients.

ACCELERATING DRUG DEVELOPMENT

We need to develop ways of developing therapies in parallel and as well as rapid testing in animal and cell models so that human trials can begin as soon as possible. Leveraging artificial intelligence and informatics platforms will also help accelerate this process.



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WHY BRING DIVERSE VOICES TOGETHER?

Through frequent communication, researchers can better understand what matters most to patients in terms of improving quality of life and the symptoms that affect them the most. Physicians, industry partners and researchers can more quickly develop accurate models and clinical trials.

HOW TO BEST SUPPORT PATIENTS?

Providing compassionate care and support to patients is crucial. Also for researchers planning clinical trials, working with patient advocacy organizations like MitoCanada will help to recruit patients early and accommodate their needs.



FINAL MESSAGE AND HOW TO GET IN TOUCH

Blaine and MitoCanada would like to thank all those who have worked with and supported them since its founding.

Visit mitocanada.org to learn more about MitoCanada and their work.

If you have any questions for Blaine, you can connect with him at blaine.penny@mitocanada.org.

