

PEP 2022

January 16-26



POMPE DISEASE: PATIENT EMPOWERMENT PROGRAM

This empowerment series is five online programs to educate and bring together Pompe disease families. Each session will include leaders in their respective fields, as well as patients themselves. The series will be held from January 16 to January 26, 2022. Each of the days runs 7-9pm ET.

For more info: cap@pompecanada.com or www.pompecanada.com/events/pep2022/

All times are eastern (ET).

DAY 1 (Sunday, Jan 16)

Conversations

7:00pm: Welcome to PEP 2022

7:15pm: A brief history of Pompe disease

We talk with Dr Reuser about the history of Pompe disease and his experience

8:00pm: The IPA, with Tiffany House

We talk with Tiffany House, Chair/Board Member of the IPA

8:30pm: High protein cooking for Pompe

Chef Lochlan shows us how we can easily increase protein in some of our meals

DAY 2 (Monday, Jan 17)

Diagnosing Pompe Disease

7:00pm: The journey from first symptoms to diagnosis & Understanding the genetics of Pompe disease

Dr Anna Lehman talks about the disease itself, diagnosing it, and its genetics

7:30pm: Family planning

Lauren Brady, genetic counsellor, talks about family planning for families affected by genetic disorders like Pompe disease

7:45pm: Newborn screening in Canada

Dr Homira Osman explains the newborn screening landscape in Canada and recent advancements

8:00pm: Newborn screening of Pompe disease

Dr Priya Kishnani talks about what we've learned about NBS for both infantile and late-onset Pompe

8:30pm: Ian's Story

Ian MacPherson, one of CAP's founders, discusses his journey with Pompe disease and recently becoming a new father!

Thank you to our sponsors: Sanofi Genzyme, Amicus Therapeutics, Asklepios BioPharmaceutical, Astellas Gene Therapies, AVROBIO, Spark Therapeutics

Canadian Association of Pompe
Association canadienne de Pompe

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DAY 3 (Wednesday, Jan 19)

Managing Pompe Disease

7:00pm: Talking to your doctor

A patient panel talks about their experiences, good and not so good, talking with their doctors

7:30pm: Nutrition

Together with Dr Seema Kanwal, a patient panel talks about the importance and challenges of nutrition

8:00pm: Mental health

David Ross joins us to share his experience starting a mental health support group for males affected by rare disease

8:30pm: Using technology

Shaneel Pathak joins us to talk about his experience and opportunities that technology gives is to manage our health, our data and contribute to research

DAY 4 (Monday, Jan 24)

Pompe disease and Your Lungs

7:00pm: Pompe disease's effect on breathing

Dr Basil Petrof discusses how Pompe disease is affecting our breathing

7:30pm: PFTs and sleep studies

Dr Basil Petrof explains pulmonary functions tests and sleep studies; what they are and how we use the information to improve our health

8:00pm: Respiratory care options

Respiratory therapist, Richard Sarada, talks about respiratory support, like BiPAP, and does a Q&A

8:30pm: Being part of a global community

Allyson Lock, Julie Garfield and Brad Crittenden talk about how we use social media to support each other, no matter where we live

DAY 5 (Wednesday, Jan 26)

Current and Emerging Therapies

7:00pm: Adjunctive therapies

Dr Dwight Koeberl discusses how we can use other therapies to add to the benefit we get from things like ERT

7:00pm: Enzyme replacement & chaperone therapies

Dr Mark Tarnopolsky discusses improvements that have been made on existing ERT, and chaperone therapy that may be in our future.

7:30pm: Gene therapy

Dr Aneal Khan talks about the current landscape and potential for gene therapy

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Speakers



Audrey Belouin
President
Canadian Association of P...



Lauren Brady, MS...
Certified Genetic Counsellor
McMaster University Medi...



Alexandra Butler
Teacher



Brad Crittenden
Executive Director
Canadian Association of P...



John H A Dyck
Past President
Canadian Association of P...



Julie Garfield
Patient Advocate
Hope Travels - Pompe Aw...



Tiffany House
Chairman/President
International Pompe Asso...



Dr. Seema Kanwal
Doctor of Naturopatic Me...
FIT TO TRAIN



Aneal Khan, MSc, ...
Assistant Professor, Depar...
MAGIC Clinic Ltd. • Discov...



Priya Kishnani, MD
C.L. and Su Chen Profess...
YT and Alice Chen Center ...



Dwight Koeberl, ...
Professor of Pediatrics, an...
Duke University Medical C...



Tricia Lee
Parent Speaker



Anna Lehman, MD...
Associate Professor of Me...
Vancouver General Hospital



Allyson Lock
President
New Zealand Pompe Netw...



Ian MacPherson
Patient Speaker



Homira Osman, P...
VP, Research and Public P...
Muscular Dystrophy Cana...



Shaneel Pathak
Co-Founder, Chief Executi...
Zamplo



Basil J. Petrof, M...
Principal Investigator, Prof...
McGill University Health C...



Dr Arnold Reuser
Researcher



David Ross
Patient Advocate
Rare Disease Mental Health



Richard Sarada
Community Respiratory T...



Sherry Simo
Nurse and mother of two



Lochlan Smyth
Chef, CAP board member



Mark Tarnopolsky...
Director of Neuromuscular...
McMaster University Medi...



Shauna VanDerKley
Wife-Mom-Grandma- Acc...

