



Quote of the Day:

“As a physician, I have learned more about Barth syndrome from the families’ posts on the Listserv than from any other single source---by far.” ~ *Richard Kelley, MD, PhD, Director, Division of Metabolism, Kennedy Krieger Institute; Professor, Pediatrics, Johns Hopkins University, Baltimore, MD; Scientific & Medical Advisory Board, Barth Syndrome Foundation*

Featured Story: A Personal Message from Aldo



Every time I am with someone from the Foundation or at the conferences I feel like I am with a family that I have known my whole life. With people outside of the Foundation it is so different because they are always worrying that something might happen or they move ahead in life because I am too slow or get hospitalized. With the Foundation we all face a lot of the same challenges and because of that we all know exactly how frustrating "normal" life can be. I am proud to be a part of this great foundation who not only is attempting to rid the world of Barth syndrome – but do it as a family.

My Barth Poem

By Aldo Dunn

Boys of all ages feeling down from syndrome

We get tired and it sucks, but we learn to deal and adjust

Our hearts are weak but our wills are strong

Some stay short, while others grow tall

We have doctors, siblings too; when we're feeling down they help us through

We take meds, some more and some few, but in the end we're feeling cool

Every other year we hold a conference, it's cool because we all stay constant

It's here we feel normal and a part of the group, because in reality we are all one big family!

Barth Syndrome Foundation

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