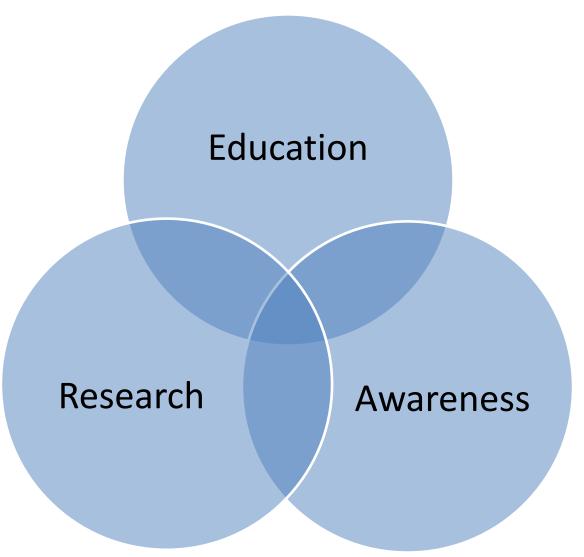


The Future Work of the APS Type 1 Foundation

Todd Talarico Robin Finch

Our Mission



Passion and Conviction can make a difference Learning from One Person's Journey - Nancy Brinker



Susan G. Komen for the Cure®

- Formerly Susan G. Komen Breast Cancer Foundation
- Founded in 1982 by Susan's sister, Nancy Brinker
- In memory of Susan G. Komen who passed away at age 39 to breast cancer

Set a Goal and Execute your Mission

- Goal □ reduce the current number of breast cancer deaths by 50% in the U.S. by 2026.
- Misson (the "how") □ eradicate breast cancer as a life-threatening disease by advancing and improving
 - Research
 - Education
 - Screening
 - Treatment



Passion and Conviction can make a difference Learning from One Person's Journey - Nancy Brinker

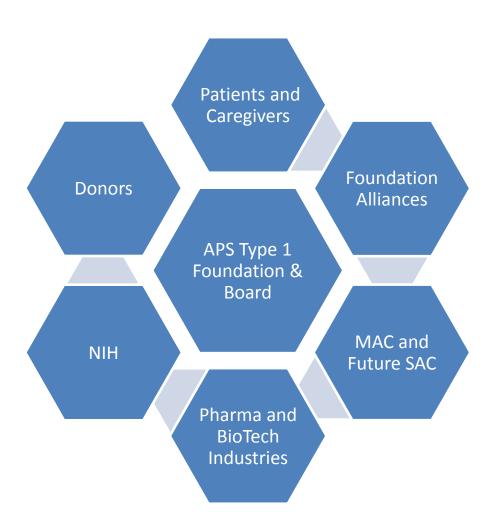


- Stay True to your Mission and Raise Awareness
 - Over \$200M raised
 - Personal involvement and commitment

 National Toll-Free Helpline
 - 1-800-I'M AWARE
 - Staffed by specially trained and committed helpline volunteers
 - Many of whom have been personally touched by breast cancer
 - Award-winning website at komen.org (100+ pages)
 - Up-to-date education regarding breast health, breast cancer
 - Foundation information
 - Links to helpful related websites
 - Established the Pink Ribbon
 - National symbol for the cause
 - 2007 trademarked the "pink running ribbon"
 - Today □ one of the largest breast cancer foundations



Who We Are





What We Have Accomplished

Fundraising for Research (Over \$600K)

Natural History
Study







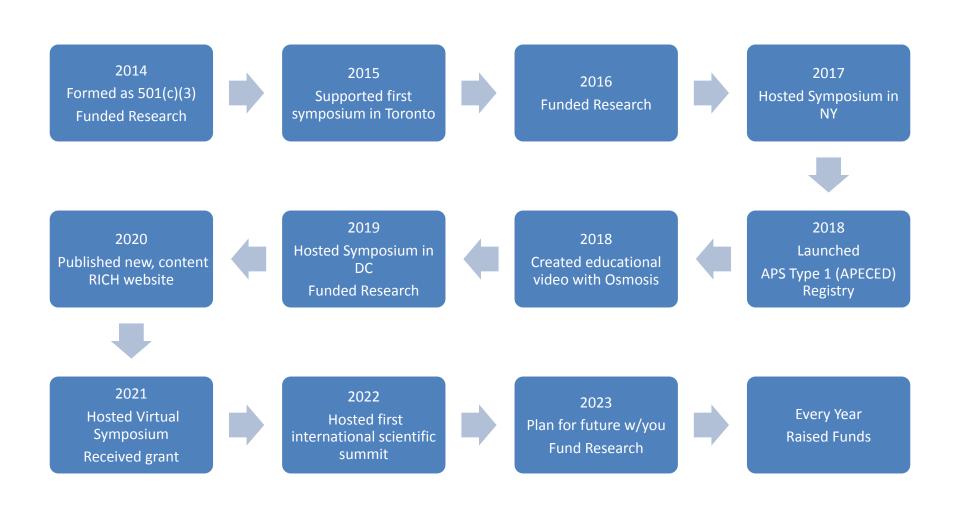






Awareness and Education

(Just a Few) Highlights from our Timeline



International Symposia on APS Type 1

Bringing our community together. Learning from one another.

















Inaugural APS Type 1 Global Scientific Summit









COHORT OVERVIEW		PREV/	ALENCE C	F THE APS	-1 COMPONENTS
Patient's cohort under review	Hypoparathyroldom			-	79%
159 patients from 148 families	Necestaneous candidates				74%
Female (89)/Male (70)=1.3	Adversil failure				67%
 Mean age 19.25 yrs. (min 2 /max 50) 	Alopecia Externacting/dispaig diarrhos			30%	
	or obliqueurs			26%	
	Teeth dysplasia			25%	
Follow-up 2000 - 2021	Deartes fallers			33% **	
Eight female patients have twelve	ypethymid usy/sperthyroidism		13%		
healthy children	Diabetes melitus		12%		
20 pts deceased (2 – 50 yrs., median 29)	Vitligo, grey har		12%		
			11%		
	Pernicious anereia		9%		
AIRE mutations	Pleas		9%		Number of components
Frequent R257* mutation in 75% of	Dry eyes, keratokonjanchisto	4%			in one patient
alleles,	Metaphyseal dysplana	3%			varied from 1 to 17
10 mutations de-novo identified	Retitis pigmentosa Anderies	3%			1 1 1 1





Where Are We Going?

Building on our vision...

Find a cure

Find our patients here and around the world

Shorten time to diagnosis

Support the LIVED experience of our patients and families

Build a global research network

Activate our patient and family community

Expand our registry for greater publication

Apply for grants...tap into the philanthropy community

Fundraise for all of the above

Fundraising: Accomplishments & Opportunities

You CAN make a difference.

Find the support journey...that works for you!

- Use the Serving Awareness campaign online
- Create your own event
- Participate in Foundation events
- Reach out to your community
- Look for company matching opportunities





Rare Disease Day 2023





Past Family Fundraisers





SEYFERT FAMILY BASKET RAFFLES







How can you help?

What can we do better?

Where are our gaps?

Beyond the Board...

Committee

Development

Share your story

Everything requires funding...how do we fundraiser smarter?



Thank you!

