



Suite 403 - Pennsylvania Place
301 Chestnut Street
Harrisburg, Pennsylvania 17101
(717) 234-2621
www.thearcpa.org

BOARD OF DIRECTORS

Jeanne Downey, President - Erie

*Kenneth Oakes, 1st Vice-President-
Philadelphia*

*William Burke, 2nd Vice-President -
Lackawanna*

*Jean Searle, Secretary -
Philadelphia*

*Michael Marsh, Treasurer -
Montgomery*

*Paul Conway, Immediate Past
President - Montgomery*

*Pat Leo, PCE Representative -
Montgomery*

M.J. Bartelmy - Mercer

Frank Bartoli - Luzerne

Jessica Capitani - Dauphin

Cynthia Dias - Greene

John Goryl - Dauphin

Karen Grady - Lehigh

Sarah Holland - Lancaster

Kurt Kondrich - Allegheny

Gerald Krall - Dauphin

Cecilia Lee - Montgomery

Nancy Murray - Allegheny

Philip Rosenbauer - Butler

Christopher Schwenk-Delaware

Joshua Stranix - Schuylkill

Sara Wolff - Lackawanna

*Maureen Cronin
Executive Director*

Dear Representative,

Warm greetings from The Arc of Pennsylvania. I am writing to share information about HB 585, introduced by Representative John Sabatina. This important legislation prevents organ transplant discrimination against people with intellectual and developmental disabilities. Discrimination against people with disabilities being considered for life-saving transplant procedures happens across the United States and in Pennsylvania. Transplant centers use neurodevelopmental status as criteria for determining transplant eligibility, even when a person's disability creates no medical impact on transplant candidacy.

This has been most recently evident in Pennsylvania for two young people with disabilities. Paul is a young man in his early 20s who needs a heart transplant, but he was denied being considered for a transplant by his doctors because he has a developmental disability. The decision to deny him consideration was not made on the basis of any medical reasons, such as lifestyle choices of alcohol consumption or anticipation that his body would reject the transplant, but specifically on the basis of his disability. Paul and his family are still fighting for him to be considered for a transplant.

This is similar to what happened to Amelia Riviera, a New Jersey child who was denied access to a kidney transplant in 2013 at the Children's Hospital of Philadelphia (CHOP) because she has an intellectual disability. This led to New Jersey passing legislation against organ transplant discrimination for people with disabilities. After a good deal of pressure and attention was brought to Amelia's case, she received a transplant at CHOP and is thriving.

Representative Sabatina has introduced HB 585, also known as "Paul's Law", which would prevent this discrimination from happening and ensure that people with disabilities are provided the same rights to access transplants as people without disabilities. The bill has bi-partisan support and is revenue neutral.

Please co-sponsor HB 585 and protect the right of people with disabilities to access lifesaving measures according to medical need instead of discriminatory misconceptions about their worth and quality of life.

The Arc of Pennsylvania is a statewide nonprofit organization that provides advocacy and resources for citizens with intellectual and developmental disabilities and their families. It was established in 1949 and currently includes 34 chapters in 57 counties, with over 8,000 members across Pennsylvania. The Arc is a grassroots, member-driven organization led by people with disabilities and their families. Local chapters provide services and advocacy for individuals with intellectual and developmental disabilities and their families, and most of our chapters provide services as well.

Please contact me with any questions you have about The Arc of Pennsylvania's support of this bill. Thank you for your work.

Sincerely,

A handwritten signature in black ink that reads 'Maureen Cronin'.

Maureen Cronin
Executive Director