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KIDNEY COMMUNITY UNITES TO URGE LAWMAKERS TO ADVANCE AND PROTECT KIDNEY HEALTH

16 kidney organizations champion legislation to increase research funding and reduce barriers to living kidney donation

Highlights

- The Alport Syndrome Foundation is one of 16 kidney health organizations who participated in Kidney Community Advocacy Day 2015 in Washington, DC.
- More than 100 advocates met with Congressional offices to call for lawmakers' support of increased research funding to accelerate development of new therapies for kidney diseases.
- Kidney health providers and patients also urged passage of legislation that eliminates barriers to living donation and helps increase access to lifesaving transplants.

More than 20 million Americans have kidney disease, the 9th leading cause of death in the U.S.

[September 10, 2015 - Washington, DC] — The Alport Syndrome Foundation is one of 16 kidney patient and health professional organizations who joined together on Capitol Hill for Kidney Community Advocacy Day 2015. More than 100 advocates met with over 100 Congressional offices to advance legislation that increases kidney research funding and removes barriers to living kidney donation. Today, more than 20 million Americans have kidney disease, nearly 650,000 of whom have kidney failure (end-stage renal disease [ESRD]) and need a kidney transplant or dialysis to stay alive.

Strengthening Kidney Research Funding for New Cures

Since 1972, the federal government has paid for most dialysis care, with less than 1% of Medicare patients accounting for nearly 7% of Medicare expenditures. The expense of the Medicare ESRD Program is a significant incentive to increase research funding to develop innovative and more cost-efficient therapies to reduce the burden of kidney disease on patients and Medicare.

Removing Barriers to Living Kidney Donation

Transplantation is the optimal treatment for most patients with kidney failure, yet every 14 minutes a patient is added to the 100,000+ person kidney waitlist and 12 Americans die each day waiting for a transplant. Transplantation is also cost effective for Medicare, with annual costs of \$32,922 per transplant patient vs. \$87,845 per hemodialysis patient.

The forthcoming Living Donor Protection Act of 2015 would help to increase the number of kidney transplants by eliminating barriers to donation, including:

- Prohibiting insurers from denying or limiting coverage or from charging higher premiums to living organ donors
- Ensuring living organ donors can use "time off" protected by the Family and Medical Leave Act to recover from donation surgery and maintain job security

To learn more about Kidney Community Advocacy Day, follow [#KidneyAdvocates](#) on Twitter.

Kidney Community Advocacy Day 2015 Participating Organizations

- Alport Syndrome Foundation
- American Association of Kidney Patients
- American Kidney Fund
- American Nephrology Nurses Association
- American Society of Nephrology
- American Society of Pediatric Nephrology
- American Society of Transplant Surgeons
- American Society of Transplantation
- Home Dialyzors United
- IGA Nephropathy Foundation of America
- National Kidney Foundation
- National Renal Administrators Association
- NephCure Kidney International
- Oxalosis and Hyperoxaluria Foundation
- Polycystic Kidney Disease Foundation
- Society for Transplant Social Workers

The Alport Syndrome Foundation is the leading non-profit organization in the United States serving and giving a voice to the community affected by this rare kidney disease that causes kidney failure, hearing loss and vision problems. The Alport Syndrome Foundation has grown to become an international presence in outreach, education and research.

For more information on the Foundation and Alport Syndrome, please visit www.alportsyndrome.org.

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