The Lymphedema Advocacy Group (LAG) is an all-volunteer patient-centered organization in the United States focused on improving access to care. Executive Director Heather Ferguson founded LAG in 2010, after the birth of her twins, one of whom has primary lymphedema.

This timeline depicts the group’s 13-year journey of building a nationwide grassroots effort and learning to navigate the American legislative system. Key elements include networking, coalition building, training and advocating advocates to communicate with legislators, and promoting research findings that demonstrate a reduction in lymphedema-related healthcare spending through better patient outcomes.

LAG’s successful strategies have resulted in wide-scale improvements to insurance coverage for compression garments and supplies for millions of Americans. We are happy to share our timeline as a blueprint for community-building, giving voice, and advancing care. Learn more about us at lymphedemaadvocacygroup.org

Advocacy Training. In 2015, we created an Advocacy Training Committee to work closely with state team members to boost their skills, confidence, and effectiveness. Our Director and volunteers have prepared hundreds of advocates for thousands of congressional meetings.

Lymphedema Lobby Days. In 2010, twelve lymphedema advocates, most of whom were founding members of LAG, made the trip to Washington, DC, to raise support for the LTA. From that point forward, until passage of the bill, our Lymphedema Lobby Days, became an annual event comprised of about 100 people from around the country who meet with hundreds of congressional offices over one or two days. Participants described the experience as “life-changing” and one of the “most inspiring and empowering” things they have done.

First Major Stakeholders. The Lymphedema Treatment Act garnered more support from congress and garnering support from local state legislators, county officials, and other elected officials. A press release from the mayor’s office went viral, and local support for the bill started growing.

Virtual Lymphedema Lobby Days. During the COVID-19 pandemic, meetings with congressional offices were moved online, which facilitated even greater participation. For any future advocacy, we plan to offer both in-person and virtual meetings options as well as call scripts.

Information cards free of charge to doctors and insurance policies do NOT cover lymphedema therapy. Without it, patients are at risk for chronic lymphatic system failure. Most physicians agree that physical and occupational therapy is the most critical component of treatment. Without it, patients are at risk for chronic lymphatic system failure.

Noonan’s Syndrome
• Progressive Encephalopathy-Hypsa Optic Atrophia
• W.I.L.D. Syndrome
• Proteus Syndrome
• Aagenaes Syndrome
• C.L.O.V.E.S. Syndrome (types 1a, 1b, 1h)
• Noonan’s Syndrome
• Sarcoma 30%
• Gynecological 20%
• Head and neck 4%
• Radiation therapy 20%
• Liver 5%
• Other 1%

The Lymphedema Treatment Act is projected to save the Medicare program $18.5m Aggregate savings of acute care, and up to an Aggregate savings of acute care, and up to an $19.8 million

Total savings associated with the coverage of lymphedema compression treatment items as proposed in the Lymphedema Treatment Act, $19.8 million

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