

# CHANGE MAKERS

## 2018 ANNUAL REPORT HIGHLIGHTS

Passionate, dedicated, amazing. That's how we describe the **change makers** of 2018—the many volunteers, partners and benefactors who made 2018 a phenomenal year. Our change makers came from all walks of life—from actor and comedian Tracy Morgan, who headlined our first annual *In Stitches* comedy fundraiser in Hollywood, and the donors who supported our posthemorrhagic hydrocephalus research campaign, to the volunteers who helped organize local WALKs to End Hydrocephalus and Community Networks. Thanks to YOU, we vastly expanded the hydrocephalus research landscape and raised awareness and much-needed funds for our research, education, support and advocacy programs. Here's a look at what made 2018 a great year:

### HA Launches Nation's First Hydrocephalus Patient Powered Registry

In 2018 we launched HAPPIER – the first hydrocephalus patient-powered registry. HAPPIER was created for our community to provide input to scientists about how hydrocephalus impacts their daily life. The information collected helps inform critical research, potentially leading to discoveries.



### 8 Scientists Awarded Grants for Hydrocephalus Research

We awarded eight scientists with research grants totaling \$1.65 million. These scientists are testing innovative new theories, drugs and interventions to prevent and stop the development of posthemorrhagic hydrocephalus (PHH) and postinfectious hydrocephalus (PIH).



### Visionaries Help Raise \$3 Million for PHH Research

On November 2, 2018, in New York City, philanthropists, business leaders, researchers, and families came together to raise national attention about hydrocephalus and funds to advance hydrocephalus research. Our Vision Dinner, generously underwritten by Craig and Vicki Brown, celebrated the completion of a three-year campaign to raise \$3 million to support a focused research initiative into PHH.

*“Since 2009, we’ve invested over \$9.2 million in cutting-edge research and our investments have paid off, with many of our scientists and clinical networks going on to secure much larger federal grants totaling \$32 million! We are thrilled to see our research program experience this resounding success and an impressive return on our investment,” said Diana Gray, Hydrocephalus Association President and CEO.*

### Record Attendance at HA CONNECT

A record-breaking 700 people attended HA CONNECT, our 15th National Conference on Hydrocephalus, in Orange County, CA. People traveled from as far as New Zealand to take part in this rich learning experience, where they connected with others impacted by hydrocephalus and gained helpful tools and resources to navigate the challenges of living with the condition. SAVE THE DATE: Our next conference is June 25-27, 2020 in Houston, TX!

### Providing Support and Advocating for Those Who Need It Most

In 2018, we provided one-on-one support to nearly 5,000 individuals via our toll-free hotline, email, and online channels. We also connected families through our 44 Community Networks around the country, and ensured that a major spending bill signed into law increased funding for important hydrocephalus-related research programs.

### Transition Paper Published in Journal of Neurosurgery

A paper summarizing the findings from our first-ever Transition Summit was published in the prestigious *Journal of Neurosurgery* (JNS). This marks the first time a major paper was published in an academic journal comprehensively highlighting the challenges faced by teens and young adults with hydrocephalus when transitioning from pediatric to adult care. Thank you to the Theodore W. Batterman Family Foundation for supporting this effort!

### WALKs Help Raise Nearly \$2 Million

Thanks to our volunteers, 43 WALKs to End Hydrocephalus were held across the U.S., with more than 14,000 participants representing over 1,200 teams. The WALKs helped raise nearly \$2 million to support HA's mission! All 43 HA WALKs are 100 percent volunteer-led.

### HA's First Comedy Fundraiser Raises \$300K for Our Mission

For one night in Los Angeles, 700 people got to hear the hilarious antics of Tracy Morgan and several other comedians while raising awareness and funds to support the Hydrocephalus Association's mission. *In Stitches: A Night of Laughs* took place April 27 in Los Angeles and was HA's first-ever comedy fundraiser. The event raised over \$300,000 for our research, support and education programs.



## JOIN US!

### DONATE NOW!

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#### THE HYDROCEPHALUS ASSOCIATION

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2018 Annual Report  
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**\$1.55M**  
INVESTED IN NEW  
RESEARCH GRANTS

**\$32M**  
RETURN ON INVESTMENT

**\$3M**  
RAISED FOR PHH RESEARCH

**14,000**  
PEOPLE TOOK PART  
IN A HYDROCEPHALUS WALK

**4,514**  
PEOPLE RECEIVED SUPPORT  
FROM HA

**44**  
COMMUNITY NETWORKS  
AROUND THE COUNTRY