

|||**|||||||||**

ADVANCED ADVOCACY ACADEMY (A3)

THE LEARNING EXPERIENCE



TABLE OF CONTENTS

- 2 At a Glance3 Objectives
- 4 Recruitment and Participation
- 7 Liver AdvoKit™
- **8** Opening Reception

Celebrating the 10th Anniversary of Global Liver Institute
Global Excellence in Advocacy Award

- 9 Day 1
- 12 Day 2
- 13 Graduation
- 14 Day 3: Hill Day
- 20 Post-Event Evaluation
- 24 Patient Testimonials
- 25 Thank You to Our Generous A3 Sponsors
- 26 Appendix: Speakers (in order of appearance)

AT A GLANCE



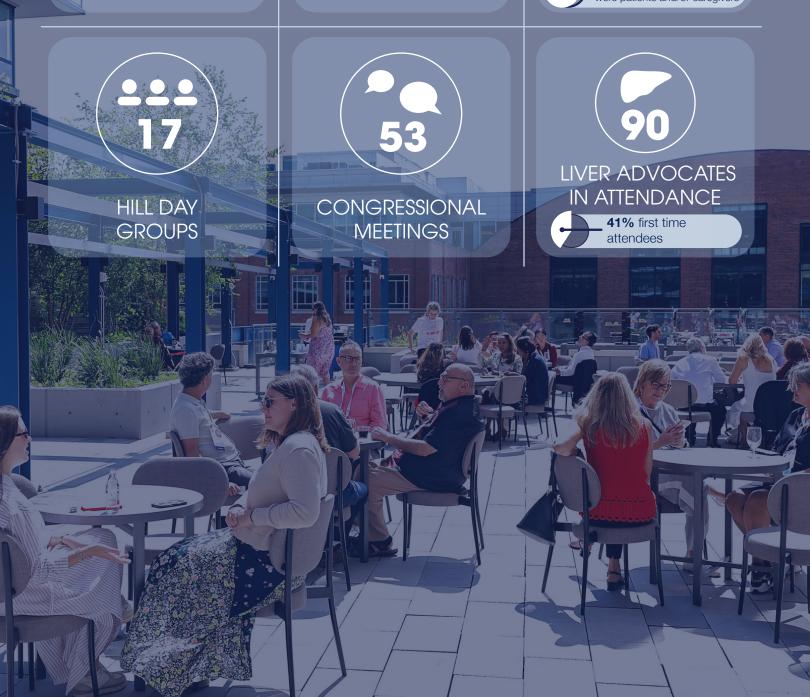
EXPERIENCE

COUNTRIES (CANADA, ENGLAND, USA)

> 19 U.S. States 2 provinces in Canada







OBJECTIVES



1. Comprehensive Education

Immerse participants in knowledge across A3's five foundational courses: Liver Literacy, Media and Storytelling, Clinical Research and Development, Navigating Healthcare and Coverage, and Understanding Healthcare Policy



2. Advocacy Skill Development

Foster advocacy expertise through interactive workshops, with a focus on effective storytelling and active participation in liver health discussions



3. Peer-to-Peer Support and Collaboration

Cultivate a supportive environment that encourages collaborative discussions and shared stories to empower participants on their liver health journeys



4. Advocacy Activation and Continuity

Equip participants with impactful advocacy tools, including the GLI Liver AdvokitTM and personalized advocacy action plans so they can translate their experiences into actionable and sustained change through the GLI Ambassador Program



5. Policy Impact

Enhance healthcare policy comprehension and involvement through the A3 Learning Experience, culminating in a Hill Day, while nurturing enduring dedication to advocacy

RECRUITMENT AND PARTICIPATION

GLI used a multi-platform outreach strategy to recruit experienced liver patients, caregivers, and professionals to apply to A3 2024.

The following techniques were employed:

- Created **shareable graphics** and sample messages featuring A3 2024 branding
- Led **outreach** on GLI's social media accounts across different platforms
- Mobilized members of the *Liver Action Network (LAN)* with requests to share information about A3 with their **local communities** through their communication channels
- Activated outreach to Liver Cancers, Fatty Liver Disease and Pediatric and Rare Liver Diseases
 Councils, requesting members to disseminate information to communities across each type of
 liver disease
- Encouraged A3 alumni to attend and refer friends, family, and others in their liver communities to apply and spread the word about A3 2024

Liver patients, caregivers, and professionals interested in participating in A3 2024 completed an online application on GLI's website to assess liver disease type or area of interest, past advocacy experience, geographical region, and other demographic factors that may pertain to future advocacy.



19 STATES

Arizona New York

California Ohio

Connecticut Oklahoma

Florida Oregon

Georgia Pennsylvania

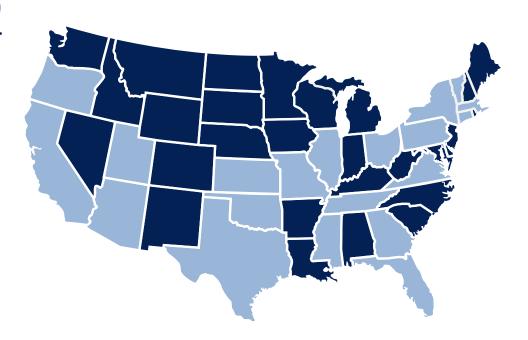
Illinois Tennessee

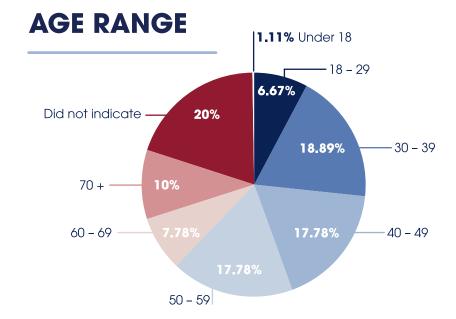
Kansas Texas

Massachusetts Utah

Mississippi Virginia

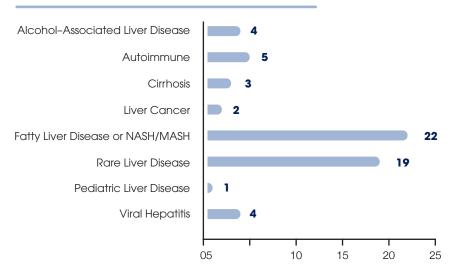
Missouri





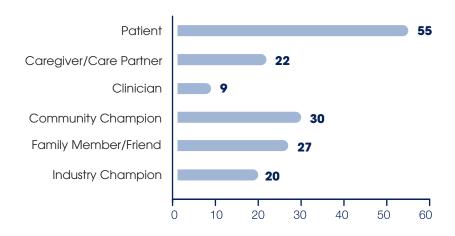
KNOWN DISEASE CONDITIONS

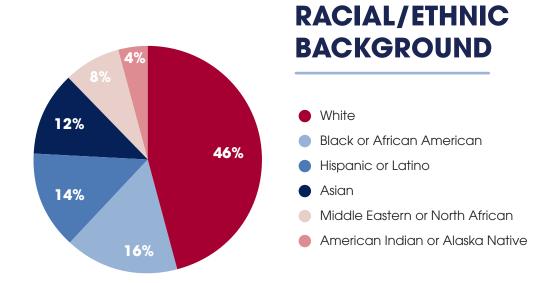
(participants able to select multiple categories)



CONNECTION TO LIVER DISEASE

(participants able to select multiple categories)







LIVER ADVOKIT TM

The Liver Advokit™ is an informative primer and workbook that complements the presentations and workshops during the A3 Learning Experience by centering on the five foundational courses of A3:

- Liver Literacy
 Media and Storytelling
 Clinical Research & Development
 Navigating Healthcare & Coverage
- 5. Understanding Healthcare Policy

Each section contains key considerations, course objectives, detailed information, and summative activities that allow advocates to develop and refine their skills.

OPENING RECEPTION

Celebrating the 10th Anniversary of Global Liver Institute

Global Liver Institute's 10th Anniversary Celebration reception, the third in a four-part series, fostered collaboration among key stakeholders and reinforced our community's commitment to advancing liver health for years to come. This special event, dedicated to patient leadership, celebrated a decade of empowering patients and caregivers, highlighting their pivotal role in shaping liver health advocacy. The evening also marked the beginning of the A3 Learning Experience weekend, setting the stage for continued progress and impact.







Global Excellence in Advocacy Award

Michael Betel, Founder and CEO of Fatty
Liver Alliance and A3 alum, received the Global
Excellence in Advocacy Award for his transformative
contributions to healthcare. His work has
driven impactful changes in raising awareness,
strengthening patient support, and advancing
community and provider education, particularly
within the fatty liver disease community.



The first day of sessions consisted of interactive presentations and workshops that empowered participants to explore different advocacy pathways that spark effective change. They learned how to leverage their expert insight and lived experiences to shape compelling stories that drive impact.



What Does It Take to Make History

GLI Founder, Donna R. Cryer, JD, discussed the attitude and mindset necessary to create lasting change and impact in the community.



Keynote Address: Investing in the Future of Care

Jason Resendez, President and CEO of the National Alliance for Caregiving, discussed the importance of caregivers to healthcare, and why the healthcare system should prioritize supporting and providing resources to caregivers to achieve better health outcomes.



Liver Literacy

Patient advocate Sophie Hansen joined nurses Alisa Corry and Lisa Stoddard to establish participants' understanding of basic liver anatomy and conditions.



From Patient to Advocate: Empowering Ourselves and the Community

Lorrinda Gray-Davis moderated as Gina Villiotti Madison and Tony Villiotti shared their liver health journeys and pathways into advocacy.



Negotiating Your Care

Kristin Hatcher, GLI's pediatric and rare liver diseases program director, informed participants about how to curate goals for a mutually agreed-upon plan with their care teams.



Confident Negotiations in Action

Kristin Hatcher moderated as expert advocates Dr. Cecilia Dueñas, Jon Potter, and Kim Martinez shared their insights from successfully negotiating and creating health action plans.



After A3: What Comes Next

Meg Didier, GLI's patient engagement manager, shared an overview of opportunities in advocacy after completion of the A3 Learning Experience.



Advocacy and Self-Care

Patient advocate Wendy Lo explored self-care techniques and resources to help maintain resilience and balance throughout the advocacy journey.



Strategies for Crafting Your Own Narrative

Christine Maalouf, GLI's communication director, and Laurie Mobley, a member of GLI's Board of Directors, shared tips and techniques to craft and refine a personal narrative as a patient or caregiver based upon the individual's healthcare journey.



Storytelling across Advocacy

Karen Hoyt guided patient advocate panelists (Stephen Silva-Brave, Jason Crutchley, Gary Miller, and Betsy Villiotti) through a conversation exploring various communication methods to reach different audiences. Panelists discussed the value of tailoring a story to improve the advocacy impact.



Crafting and Tailoring Your Story for Different Audiences

Karen Hoyt and Jeff McIntyre, GLI's VP of liver health programs, worked with GLI Ambassadors at each table to guide participants in crafting personal narratives to be shared across specific advocacy settings.



Fireside Chat

Donna R. Cryer, JD, and Melodie Narain-Blackwell, a member of GLI's Board of Directors, discussed the impact of mentorship and looked back at Donna's career and impact with GLI. The session closed with a video tribute featuring friends and staff of the organization from over the decade who shared about Donna's impact on their lives.



Closing Session

Joel Ballew, GLI's director for strategic partnerships, closed the day with a discussion about the importance of bringing learning to life and applying the skills gained at A3 to create lasting change in communities.



Participants built on the previous day's skills on day two. They learned how to leverage personal experiences for change with experts who highlighted the positive impact of patient-driven initiatives.



Regulating Drug Company Promotion: Influencers and Social Media

Sneha Dave, Executive Director of Generation Patient, discussed the importance of advocating for accurate information regarding the advertisement of medications and treatments on social media on both individual and communal fronts.



Demystifying Clinical Trials and Research

Michael Betel and Dr. Ahmad Anouti explained the purpose of each phase of clinical trials, from safety assessment to post-market surveillance, and shared key considerations at each point in the process.



Empowering Your Healthcare Journey: Navigating Patient Portals and Advocating for Your Rights

Participants learned how and why to take charge of their own medical records from Kristin Hatcher. She shared key techniques to navigate digital health tools and how to use digital tools to exercise autonomy in healthcare decisions.



What is Your Role in Policy as an Advocate: Making Hill Day Impactful

Lorrinda Gray-Davis guided advocates Bruce Dimmig, Dr. Cecilia Dueñas, and April Hubbard as they shared examples to determine what information is vital to impactful legislative visits and shared advice to cultivate long-term relationships with representatives.



Understanding Policy & A3 Hill Day Briefing

GLI CEO Larry R. Holden and Sara van Geertruyden, Partner at Thorn Run Partners, equipped advocates with the knowledge, skills, and resources needed to effectively communicate important messages and advocate for liver health priorities to policymakers on Capitol Hill.

GRADUATION:

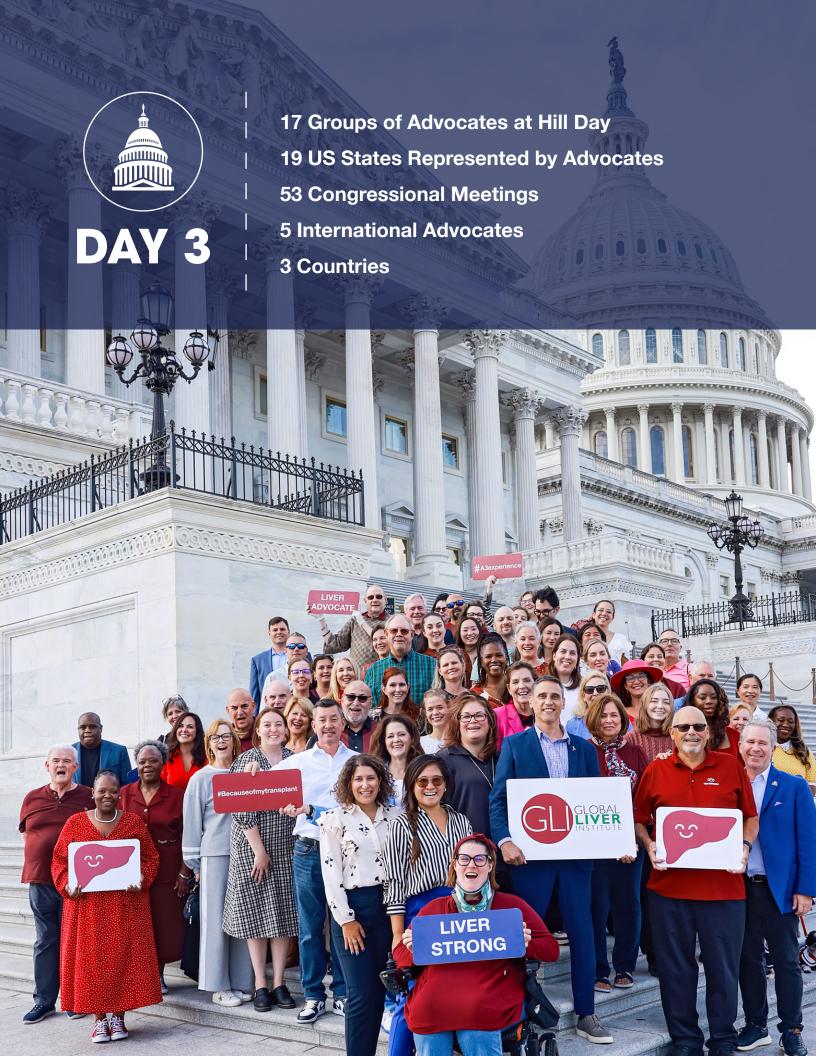
Victor Reyes, the Chair of GLI's Board of Directors, extended his congratulations to the A3 Class of 2024. During his speech, Victor expressed admiration for the significant contributions that each participant had made to the liver community. Board members Victor Reyes and Shonta Chambers, along with GLI CEO, Larry R. Holden, presented each advocate with a certificate of achievement for completing the A3 program.











On the final day of the program, graduates had the opportunity to put their newly acquired skills into action by participating in a Hill Day on Capitol Hill in Washington, D.C. Teams of advocates met with Congressional offices to share their concerns about the need for early diagnosis of liver cancer through multi-cancer screenings, medical nutrition equity, preventive services such as obesity treatment, clinical lab services to detect and manage liver disease, policies supporting living donors, and more.

ADVOCATES MET WITH THE OFFFICES OF

ricp. Otoprianic bicc (it ort

Rep. Mike Carey (R-OH)

Rep. Sean Casten (D-IL)

Rep. Joaquin Castro (D-TX)

Rep. Lori Chavez-DeRemer (R-OR)

Rep. Gerald Connoly (D-VA)

Rep. Christopher Deluzio (D-PA)

Rep. Danny Davis (D-IL)

Rep. Lloyd Doggett (D-TX)

Rep. Mike Ezell (R-MS)

Rep. Dwight Evans (D-PA)

Rep. Jim Himes (D-CT)

Rep. John Joyce (R-PA)

Rep. Mike Levin (D-CA)

Rep. Debbie Lesko (R-AZ)

Rep. Frank Lucas (R-OK)

Rep. Celeste Maloy (R-UT)

Rep. Andrew Ogles (R-TN)

Rep. Chip Roy (R-TX)

Rep. John Rutherford (R-FL)

Rep. Greg Stanton (D-AZ)

Rep. Mike Thompson (D-CA)

Rep. Robert Wittman (R-VA)

Sen. Marsha Blackburn (R-TN)

Sen. Richard Blumenthal (D-CT)

Sen. Sherrod Brown (D-OH)

Sen. Laphonza Butler (D-CA)

Sen. John Cornyn (R-TX)

Sen. Bob Casey (D-PA)

Sen. Dick Durbin (D-IL)

Sen. Kirsten Gillibrand (D-NY)

Sen. Bill Hagerty (R-TN)

Sen. Josh Hawley (R-MO)

Sen. Tim Kaine (D-VA)

Sen. Mark Kelly (D-AZ)

Sen. James Lankford (R-OK)

Sen. Mike Lee (R-UT)

Sen. Roger Marshall (R-KS)

Sen. Jeff Merkley (D-OR)

Sen. Markwayne Mullin (R-OK)

Sen. Chris Murphy (D-CT)

Sen. Alex Padilla (D-CA)

Sen. Mitt Romney (R-UT)

Sen. Chuck Schumer (D-NY)

Sen. Rick Scott (R-FL)

Sen. Kyrsten Sinema (I-AZ)

Sen. Jon Ossoff (D-GA)

Sen. Marco Rubio (R-FL)

Sen. J.D. Vance (R-OH)

Sen. Mark Warner (D-VA)

Sen. Raphael Warnock (D-GA)

Sen. Roger Wicker (R-MS)

Sen. Ron Wyden (D-OR)

HILL DAY GROUPS

ARIZONA

STAFFERS AND LEGISLATORS

Katherine Phillips, Sen. Mark Kelly (D-AZ)

Sylvia Lee, Sen. Kyrsten Sinema (I-AZ)

Michael Nudo, Rep. Debbie Lesko (R-AZ)

Mia Rubio, Rep. Greg Stanton (D-AZ)

GROUP MEMBERS

Bruce Dimmig

Kylee Newgass

Barbara Lee

Robin Tenny

Mario Remo

Brenda Remo

CALIFORNIA



STAFFERS AND LEGISLATORS

Lauren Battle, Sen. Laphonza Butler (D-CA)

John Chambliss, Sen. Alex Padilla (D-CA)

Tyler Adams, Rep. Mike Thompson (D-CA)

Ali Feinswog, Rep. Mike Levin (D-CA)

★ GROUP MEMBERS

Cecilia Dueñas

Jon Potter

Wendy Lo

Maryanne Peng

Carlos Redmond

CONNECTICUT



STAFFERS AND LEGISLATORS

Sydney Lamb, Sen. Richard Blumenthal (D-CT)

Sebastián Cardona-Negrón, Sen. Chris Murphy (D-CT)

Kaleigh Calvao, Rep. Jim Himes (D-CT)

★ GROUP MEMBERS

Luiz Cordeiro

Gary Miller

FLORIDA



STAFFERS AND LEGISLATORS

Kevin Alkinburg, Rep. John Rutherford (R-FL)

Nicole Wright, Sen. Marco Rubio (R-FL)

Jared Honts, Sen. Rick Scott (R-FL)

GROUP MEMBERS

Lezlee Peterzell-Bellanich

Jerry Rosenberg

Kevin Tyler

AJ Michaels

GEORGIA



STAFFERS AND LEGISLATORS

Chelsey Murphy, Sen. Jon Ossoff (D-GA)

Gabriella Vesey, Sen. Raphael Warnock (D-GA)

+ GROUP MEMBERS

Rhonda Rowland

ILLINOIS



STAFFERS AND LEGISLATORS

Sue Ellen Wilk, Sen. Dick Durbin (D-IL)

The office of Rep. Danny Davis (D-IL)

Lucy Schmitz, Rep. Sean Casten (D-IL)

Ethan Gunnlaugsson, Rep. Brad Schnieder (D-IL)

★ GROUP MEMBERS

L. Marie Asad

Avalon Gordon

Kerry Sivia

KANSAS



STAFFERS AND LEGISLATORS

Max Seltzer, Sen. Roger Marshall (R-KS)

Eric Dunay, Rep. Sharice Davids (D-KS)

♣ GROUP MEMBERS

Melaine Smith

MISSISSIPPI

STAFFERS AND LEGISLATORS

Katy Roberts, Sen. Roger Wicker (R-MS)

Allie Cameron, Rep. Mike Ezell (R-MS)

★ GROUP MEMBERS

Elisabeth Naff

MISSOURI

STAFFERS AND LEGISLATORS

KS 🛨

GROUP MEMBERS

Alex Gorman, Sen. Josh Hawley (R-MO)

Laura Bonebrake

NEW YORK

STAFFERS AND LEGISLATORS

Claudia Brady, Sen. Chuck Schumer (D-NY)

Catherine Paul, Sen. Kirsten Gillibrand (D-NY)

GROUP MEMBERS

Daniel Grimm

OHIO

STAFFERS AND LEGISLATORS

Robert Orr, Sen. J.D. Vance (R-OH)

Emily Graeter, Rep. Mike Carey (R-OH)

GROUP MEMBERS

Susan Horava

OKLAHOMA



STAFFERS AND LEGISLATORS

Layne Greenwood, Sen.James Lankford (R-OK)

Jake Johnson, Sen. Markwayne Mullin (R-OK)

Jill Rammrath, Rep. Stephanie Bice (R-OK)

Georgia Davies, Rep. Frank Lucas (R-OK)

GROUP MEMBERS

Jeff Collins

Lorrinda Gray-Davis

Donna Kincaid

Karen Hovt

OREGON

STAFFERS AND LEGISLATORS

Becca Damante and Julia Brunner, Sen. Jeff Merkley (D-OR)

Naod Aynalem, Sen. Ron Wyden (D-OR)

Francisco Flores-Pourrat, Rep. Lori Chavez-DeRemer (R-OR)

GROUP MEMBERS

Natasha Durant

PENNSYLVANIA

STAFFERS AND LEGISLATORS

Zoey Keely, Sen. Bob Casey (D-PA)

Manny Burton, Rep. Christopher Deluzio (D-PA)

Laura Guerra, Rep. Dwight Evans (D-PA)

Tyler Mortier, Rep. John Joyce (R-PA)

GROUP MEMBERS

Maria Hernandez

Leigh Silverang

Leslie Castro

Betsy Villiotti

18 2024 Summary Report

TENNESSEE



STAFFERS AND LEGISLATORS

Jillian Cantrell, Sen. Bill Hagerty (R-TN)

Christopher Kelly, Sen. Marsha Blackburn (R-TN)

Nathan Royce with Rep. Andrew Ogles (R-TN)

★ GROUP MEMBERS

Teresa Davidson

Tamika Smith

Norene Devoria Smith

Tabitha Derryberry

Mimi Smith

TEXAS



STAFFERS AND LEGISLATORS

Lilly Walsh, Sen. John Cornyn (R-TX)

Michael Davis, Rep. Chip Roy (R-TX)

Meghan Hunt, Rep. Lloyd Doggett (D-TX)

Eyole Mbongo, Joaquin Castro (D-TX)

GROUP MEMBERS

Ahmad Anouti

Aya Sukkar

Jennifer Berg

Catina Davis

Rose Hernandez

Stephen Silva

UTAH



STAFFERS AND LEGISLATORS

Stephen Hansen, Sen. Mike Lee (R-UT)

Grace Simmons, Sen. Mitt Romney (R-UT)

Nathan Tenney, Rep. Celeste Maloy (R-UT)

GROUP MEMBERS

Sophie Hansen

VIRGINIA

STAFFERS AND LEGISLATORS

Jonah Kim, Sen. Mark Warner (D-VA)

Siobhan Murray, Sen. Tim Kaine (D-VA)

Jamie Smith, Rep. Gerald Connolly (D-VA)

Andrew Maloney, Rep. Robert Wittman (R-VA)

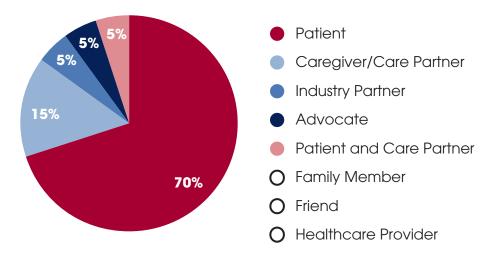
+ GROUP MEMBERS

Scott Salvaggio

Jason Crutchley

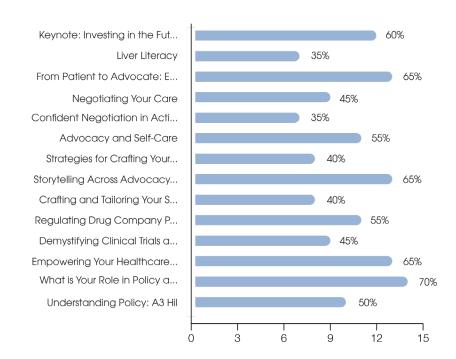
POST-EVENT EVALUATION

What role do you identify with in the liver community?

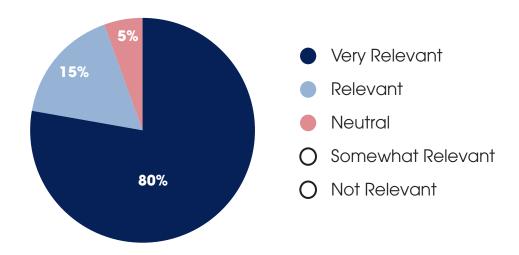


Which session(s) did you find the most valuable?

(check all that apply)



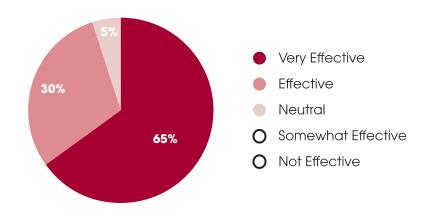
How valuable was the content in supporting your work as an advocate?



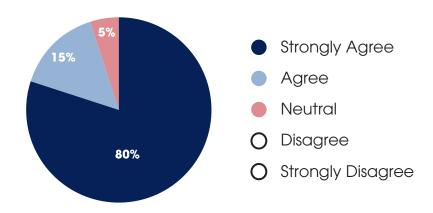
What key takeaways or lessons did you gain from the A3 sessions?

- I got a better understanding on how to be an advocate and a teacher and how to go forward in our community."
- I learned that everyone's story is important and that there is no such thing as an ignorant question or thought. Someone in the room probably has experienced what you are going through or have experienced as well. The art of storytelling varies and it is up to us to decide how we want to share our experiences."
- That as patients we need to lead the way fighting for better care and making liver disease more aware to everyone."

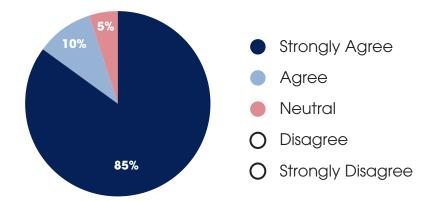
How effective were the networking opportunities in helping you build valuable connections or relationships during the event?



Are you better equipped to continue your advocacy journey after attending A3?



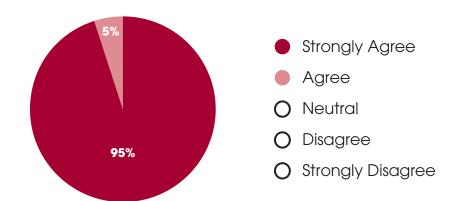
The speakers and facilitators were engaging and knowledgeable



How do you plan to apply the information or insights gained to your advocacy work?

- Work with GLI and advocate in helping those in my support groups. I also hope to work with those I networked with at the conference and continue to grow and build my community so that I am better able to meet the needs of those I advocate for. I also strive to make things better for those newly diagnosed with liver disease. Earlier detection and education is essential as our liver regenerative ability is a gift and if we can help early on to get people assistance so they do not end up cirrhotic by from MASH like myself."
- I hope to take whatever I've learned and into teaching at local area schools, their driver side classes and their anatomy classes about the importance of being an organ donor."
- I plan to apply the insights gained from the A3 sessions to strengthen my advocacy work by being more effective in communicating my story and the stories of others, which I learned through the narrative-focused sessions. I intend to use the negotiation techniques discussed to advocate more confidently and ensure that patients' voices are heard in healthcare settings. The knowledge about policy and the role of government agencies will help me navigate and influence healthcare policies more effectively, allowing me to better support those I advocate for and to drive meaningful changes in the system. Overall, these insights have equipped me with the tools needed to be a more informed, strategic, and impactful advocate."

I would recommend the Advanced Advocacy Academy (A3) to another individual within the liver health community



PATIENT TESTIMONIALS

- I am very appreciative to everyone for all the hard work it took to plan A3! I already miss my GLI friends! I can't wait to make a difference in the world being much more equipped thanks to GLI!"
- I appreciate what was given to me. I am profoundly changed, and more prepared to make change."
- **ff** We are the voice of change."
- I have a strong passion to educate and impact those who have been diagnosed with MASH but had no idea what that looked like. After listening to the speakers and meeting seasoned advocates I have a much better idea of the path I need to take."
- This experience for me has been life changing. I can't thank you all enough for giving me this opportunity."

THANK YOU TO OUR GENEROUS A3 SPONSORS

BURGUNDY





GOLD











SILVER





CONTRIBUTORS









APPENDIX: SPEAKERS

Donna R. Cryer, JD

Founder

Global Liver Institute

Jeff McIntyre

Vice President, Liver Health Programs Global Liver Institute

Karen Hoyt

Educator and Patient Advocate Founder, ihelpc LLC

Jason Resendez

President and CEO

National Alliance for Caregiving

Sophie Hansen

Patient Advocate

Alisa Corry, NP

Intermountain Healthcare

Lisa Stoddard, NP

Intermountain Healthcare

Lorrinda Gray-Davis

President

Transplant Recipients International Organization (TRIO)

President and Founder

TRIO Oklahoma

Anthony (Tony) Villiotti

Founder

NASH kNOWledge

Gina Madison Villiotti

Executive Director

NASH kNOWledge

Kristin Hatcher

Program Director, Pediatric and Rare

Liver Diseases

Global Liver Institute

Cecilia Dueñas, PsyD

Clinical Psychologist Patient Advocate

Jon Potter

Patient Advocate

Kimberly Martinez

Patient Advocate

Wendy Lo

Patient Advocate
Wendy Lo Consulting, LLC

Laurie Mobley

Executive Vice President, BRG Communications Board of Directors, Global Liver Institute

Christine Maalouf

Director, Communications
Global Liver Institute

Stephen Silva-Brave

Patient Advocate

Jason Crutchley

Patient Advocate

Gary Miller

Patient Advocate

Betsy Villiotti

Vice President NASH kNOWledge

Melodie Narain-Blackwell

President and Founder, Board Chair Color of Gastrointestinal Illnesses Board of Directors, Global Liver Institute

Joel Ballew

Director, Strategic Partnerships Global Liver Institute

Michael Betel

Founder and CEO Fatty Liver Alliance Chair, GLI Liver Action Network

Ahmad Anouti, MD

Postdoctoral Research Fellow in Hepatology University of Texas Southwestern

Bruce Dimmig

Patient Advocate

April Hubbard

Patient Advocate

Cat Evans

Director, Program Operations Global Liver Institute

Scott Salvaggio

Patient Advocate

Larry R. Holden

President and Chief Executive Officer Global Liver Institute

Sara van Geertruyden

Partner, Thorn Run Partners



For full program agenda and speaker details please scan this QR code







globalliver.org

info@globalliver.org (800) 845-5910



www.globalliver.org



@GlobalLiver



@GlobalLiverInstitute





Global Liver Institute

Global Liver Institute (GLI) is a 501(c)3 nonprofit organization founded in the belief that liver health must take its place on the global public health agenda commensurate with the prevalence and impact of liver illness. GLI promotes innovation, encourages collaboration, and supports the scaling of optimal approaches to help eradicate liver diseases. Operating globally, GLI is committed to solving the problems that matter to liver patients and equipping advocates to improve the lives of individuals and families impacted by liver disease. GLI holds Platinum Transparency with Candid/GuideStar, is a member of the National Health Council, and serves as a Healthy People 2030 Champion. Follow GLI on Facebook, Instagram, LinkedIn, and YouTube or visit www.globalliver.org.

EIN: 46 - 4687212











2024 SUMMARY REPORT



