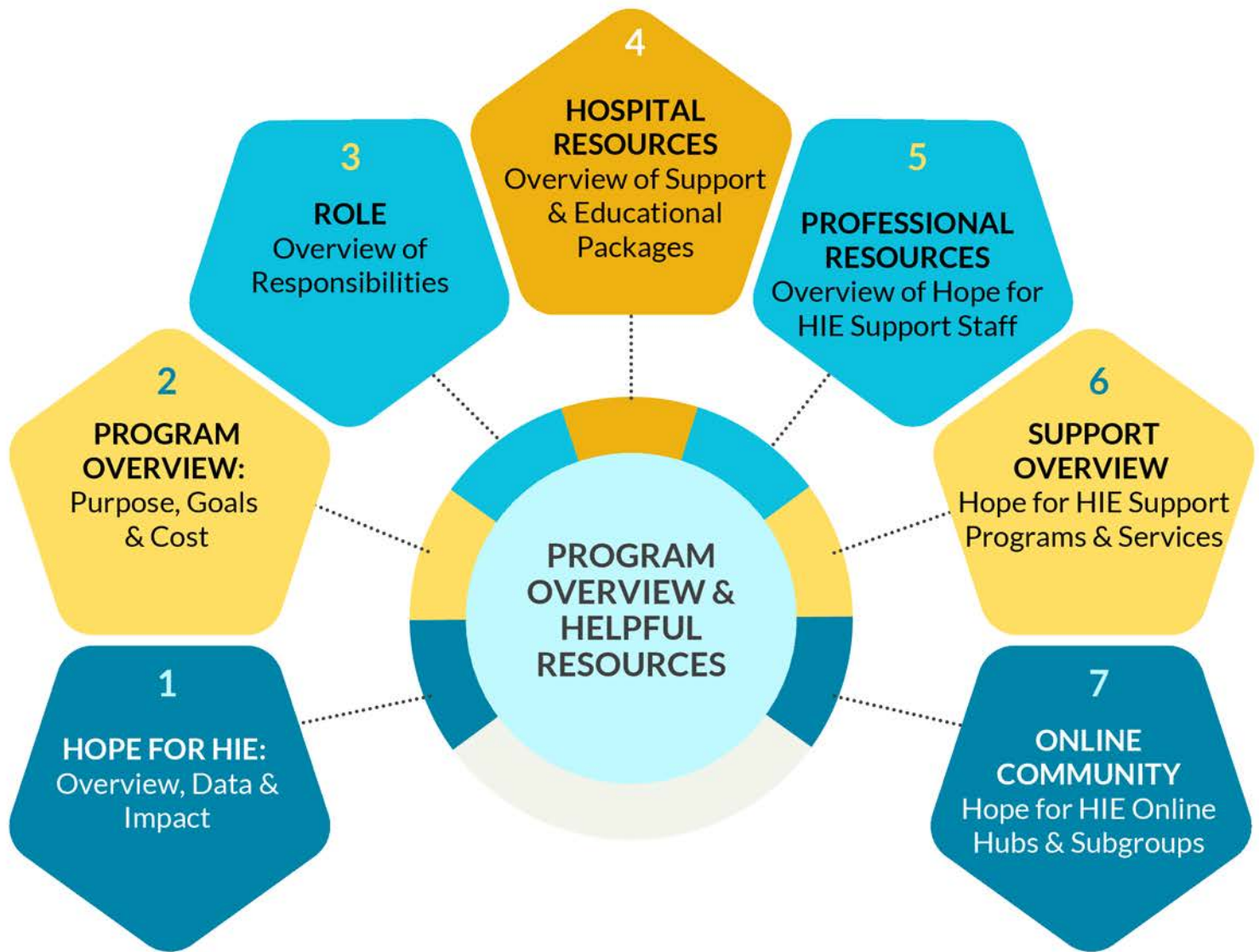




HIE HOSPITAL AMBASSADOR ROADMAP

Click on each section for a detailed overview of the next steps.



TO CONNECT IN, VISIT:

HIE.SUPPORT

@HOPEFORHIE & HOPEFORHIE.ORG



HOPE for HIE :OVERVIEW, DATA & IMPACT

HISTORY & MISSION:

- [Hope for HIE](#) is the premiere global organization dedicated to improving the quality of life for children and families impacted by Neonatal & Pediatric Acquired Hypoxic Ischemic Encephalopathy (HIE) through awareness, advocacy, education, support, and research.
- The Hope for HIE Foundation is a US-based 501(c)3 non-profit organization serving families worldwide. We have a [history](#) of expansive growth, starting in 2010 as a small online group for a few hundred parents, evolving into a nonprofit in 2014, and now supporting over 10,000 families worldwide.
- Our [mission](#) is focused on improving the quality of life for children and families impacted by neonatal and pediatric-acquired Hypoxic Ischemic Encephalopathy, a type of brain injury that has a spectrum of outcomes and the myriad of ways it may impact a baby or child in their lifetime.

TEAM OF RESOURCES:

>> STAFF

- Executive Director
- Program Manager
- Certified Social Worker
- Certified Child Life Specialist & Grief Counselor
- Clinical Research Program Manager
- Peer Support Coordinator
- Program Coordinator
- Administrative Assistant

>> MEDICAL ADVISORY BOARD

- 35+ Multidisciplinary specialists
- Clinical and research-based
- Some parent providers are members
- Advise on organizational priorities & projects
- Advocate on behalf of the organization in applicable spaces

>> BOARD OF DIRECTORS

- All-volunteer
- All patient families connected to HIE
- Diverse perspectives
- Credentialed professionals:
 - CPA
 - Pediatric Neurologist
 - Pediatric Occupational Therapist
 - Professional Fundraising

>> PARTNERS IN HOPE

- Meaningful Corporate Partnerships: Mutuality in mission and focus
- Ensure sustainability of resources for the organization

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HOPEfor HIE : OVERVIEW, DATA & IMPACT

LONGITUDINAL SUPPORT RESOURCES

>> REFERRALS

As part of the Child Neurology Foundation’s Neurological Social Services Network (NSSN), we have access to localized resources for families in need and can facilitate bi-directional [referrals](#).

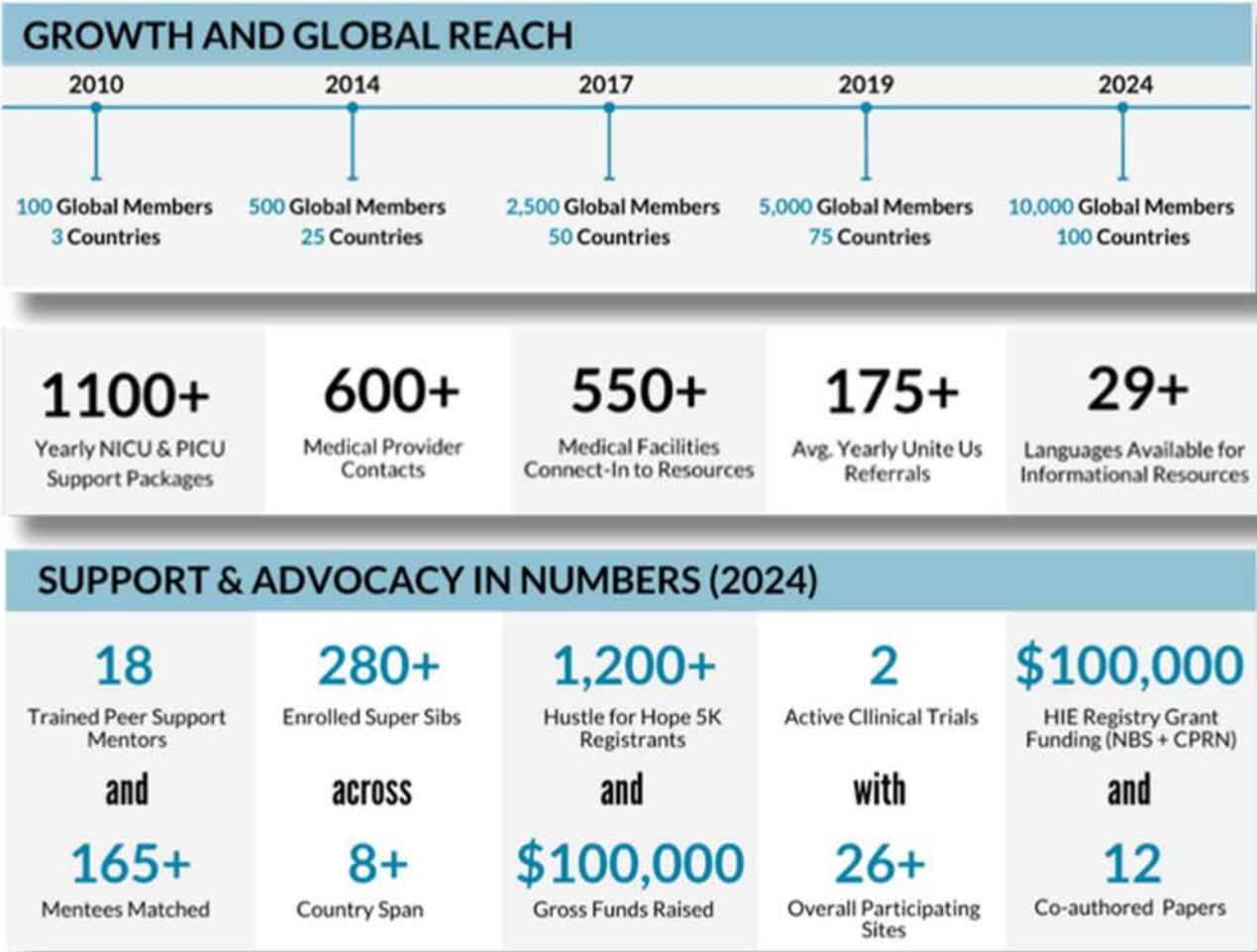
>> SUPPORT RESOURCES AT TIME OF DIAGNOSIS

We’re expanding resources to educate HIE families, clinicians, and researchers, available free of charge in print to NICUs, PICUs, clinics, and other support entities. We also offer support boxes for newly diagnosed families, distributed in NICUs and PICUs. Request materials [here](#).

>> LONG TERM SUPPORT RESOURCES FOR FAMILIES

We offer a range of services for HIE families of all ages and outcomes, including bereavement and loss support, sibling resources, and demographic-specific assistance. These programs are accessible worldwide to support families in need. See our [Support Resources Overview](#) for more details.

DATA & IMPACT (2024)



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HIE HOSPITAL AMBASSADOR: PROGRAM OVERVIEW

PROGRAM GOALS:

>> SUPPORT:

Improve family outcomes by connecting families to Hope for HIE's tailored support and resources

>> EQUITY:

Bridge the gaps for families, coordinating longitudinal resources for a cohesive and comprehensive care experience

>> EMPOWERMENT:

Ensure every family feels empowered, connected, and supported on their HIE journey

AMBASSADOR PROFILE & SELECTION PROCESS



HIE HOSPITAL AMBASSADOR: PROGRAM OVERVIEW

PROGRAM ELEMENTS:

>> SUPPORT MATERIALS:

Hope for HIE will provide unlimited support packages, educational materials, and event flyers to the identified touchpoints (NICU, PICU, outpatient clinics)

>> DEDICATED, TRAINED AMBASSADOR

- Trained in peer support, ambassador role, and best practices in communication, facilitation
- Dedicated human resource for families to connect with
- Coordination of quarterly events for local HIE families
- Community resource building in conjunction with hospital/health system so families have better coordination of care and understanding

>> COMMUNITY RESOURCE LIST

Building a collaborative repository of community resources, in collaboration with the health system and local community agencies

>> HOPE FOR HIE PROGRAMS, SERVICES & STAFF

- Hospital team and engaged families will receive access to Hope for HIE's comprehensive programs and services.
- Hospital clinical staff will also have access to Hope for HIE's social worker, child life specialist and other staff to best serve families.

PROGRAM COSTS

>> \$2,500 ANNUALLY

- The HIE ambassador is contracted through Hope for HIE, minimizing the resourcing needed to go through hiring/contracting in complex health systems.
- Hope for HIE manages the oversight of any health system-related compliance, training, etc. that may be required for the ambassador.

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ROLE: OVERVIEW OF RESPONSIBILITIES

ROLES OF AN HIE HOSPITAL AMBASSADOR

CONDUIT OF CONNECTION

Ambassadors serve as a bridge—linking families to the people, programs, and resources that help them feel supported every step of the way on their HIE journey.



01 - Family Liaison

Connects families with Hope for HIE's dedicated support staff to help them feel supported on their HIE journey, including:

- *Social Worker*
- *Child Life Specialist*
- *Grief Counselor*

Guides families to Hope for HIE's programs, services, and support networks for the whole family, across the range of impacts & outcomes.

03- Research & Education

Informs families of the latest health literacy resources and opportunities, including:

- *Clinical research & study opportunities*
- *Medical Advisory Board Educational Q&As*
- *Child Life Q&As*
- *HIE Peer Perspective Series*

04- Advocacy & Connection

Encourages families to get involved in advocacy & volunteering efforts:

- *Care/translation committees*
- *PSMs and Hospital Ambassadors*

Fosters connection through local community events:

- *Quarterly in-person meetups*
- *Annual Hustle for Hope 5K*

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HOSPITAL RESOURCES: OVERVIEW OF SUPPORT & EDUCATIONAL PACKAGES

NICU SUPPORT PACKAGE

[\[HopeforHie.org/RequestMaterials\]](https://HopeforHie.org/RequestMaterials)



NICU SUPPORT PACKAGE provides newly diagnosed families with:

- Baby hat & Swaddle
- Hope for HIE Coffee Mug
- Rubber Duck
- Folder, Notebook, & Pen
- Support Services Connection Card
- NICU Timeline for Parents
 - English
 - Spanish
 - Arabic
 - German
 - French
 - Hindi
 - Mandarin
 - Hebrew
 - More upon request!

PICU SUPPORT PACKAGE

[\[HopeforHie.org/RequestMaterials\]](https://HopeforHie.org/RequestMaterials)



PICU SUPPORT PACKAGE provides newly diagnosed families with:

- Drawstring Bag
- Hope for HIE Coffee Mug
- Folder, Notebook, & Pen
- Support Services Connection Card
- PICU Timeline for Parents
 - English
 - Spanish
 - Arabic
 - German
 - French
 - Hindi
 - Mandarin
 - Hebrew
 - More upon request!

HOSPITAL RESOURCES: OVERVIEW OF SUPPORT & EDUCATIONAL PACKAGES, CONTINUED

LOSS SUPPORT PACKAGE

[\[HopeforHie.org/RequestMaterials\]](https://www.hopeforhie.org/RequestMaterials)



LOSS SUPPORT PACKAGES are available for hospitals to order; otherwise, families can request them via the form below. It includes:

- Commemoration Candle
- Handwritten Card from Loss Parent (depending on availability)
- Loss Support and Connection Card with Overview of Bereavement and Loss Services
- Hope for HIE Board of Directors In Remembrance Note

Loss & Commemoration Family Request Form:
[Linked Here](#)

EDUCATIONAL BROCHURES

[\[HopeforHie.org/RequestMaterials\]](https://www.hopeforhie.org/RequestMaterials)



NICU TIMELINE: ENGLISH & SPANISH

PICU TIMELINE: ENGLISH & SPANISH

CLICK FOR DOWNLOAD OR TO PRINT

PROFESSIONAL RESOURCES: OVERVIEW OF HOPE FOR HIE'S SUPPORT STAFF

PROFESSIONAL STAFF



CERTIFIED SOCIAL WORKER - JENNIFER SCHAEFER, CAPSW

Provides personalized emotional guidance and support, professional and peer connection via weekly video support groups, and access to Hope for HIE and/or local resources, support programs and services.



CERTIFIED CHILD LIFE SPECIALIST- ANNIE GUNNING, CCLS, GC-C

Provides personalized coping plans, developmentally appropriate resources for HIE children and siblings, parent coaching, and peer support programs focused on coping skills and therapeutic play.

CERTIFIED GRIEF COUNSELOR

Provides bereavement and loss support, helping families navigate their grief journey through legacy building, meaningful memory-making, and personalized guidance.



COMMUNITY RESOURCE NETWORK - UNITE US

As part of the Child Neurology Foundation's Neurological Social Services Network (NSSN), we have access to localized resources for families in need and can facilitate bi-directional referrals.

ADDITIONAL HOPE FOR HIE STAFF



CLINICAL RESEARCH PROGRAM MANAGER - MAGGIE JALOWSKY

Bridges the gap between families and research, ensuring that real-life experiences shape the future of HIE care. By managing studies, building partnerships, and guiding initiatives such as the HIE Registry, this role enables families to actively contribute to research that truly reflects their needs.



PEER SUPPORT COORDINATOR - ALLISON MOISE, BSW

Connects families with trained peer support mentors who can offer guidance, support, and shared, lived experience. She begins by reviewing applications for the various mentorship programs, including 1:1 support along the journey, loss mentorship, and on-call support.



PROGRAM MANAGER - DEANNA BRYAN

Oversees fulfillment, manages key projects and campaigns - including the annual Hustle for Hope 5K - and coordinates educational initiatives that support families across the HIE journey, including the MAB Q&A series, and more.

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SUPPORT OVERVIEW: HOPE FOR HIE'S SUPPORT PROGRAMS & SERVICES

SOCIAL WORK PROGRAMS & SERVICES

[\[HIE.SUPPORT\]](#)



PEER SUPPORT MENTORSHIP

Provides sustained 1:1 or on-call mentorships across all ranges, impacts, and outcomes. Mentors and mentees are paired through a process facilitated by our social worker and peer support coordinator.



MONTHLY VIRTUAL SUPPORT GROUPS

Facilitated by our social worker, these closed Zoom experiences create a space for families to connect, share, and find healing and hope across all ranges, impacts, and outcomes.



HIE HOSPITAL AMBASSADOR PROGRAM

Ambassadors act as a conduit of connection between their local hospitals and Hope for HIE's longitudinal support resources to improve family outcomes and cohesiveness of care.

LOSS & BEREAVEMENT SUPPORT SERVICES

[\[HopeforHie.org/Parents/LossSupport\]](https://HopeforHie.org/Parents/LossSupport)

Social Worker Services



Child Life Services



Peer Support for Parents facing HIE Loss



Video Support Groups



Remembrance Commemoration Gift



Online Memorial Submissions



Super Sibs Support Program



Peer Support for Extended Family facing HIE Loss



VISIT FOR
LINKS AND
DETAILS

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SUPPORT OVERVIEW: HOPE FOR HIE'S SUPPORT PROGRAMS & SERVICES



[HIE.SUPPORT]

VISIT FOR LINKS
AND DETAILS

CHILD LIFE PROGRAMS & SERVICES



SOAR PROGRAM

The SOAR (Support, Ownership, Advocacy, Resilience) program helps children with HIE (ages 7+) develop self-advocacy skills, build peer connections, and navigate their journeys with confidence.



SUPER SIBS PROGRAM

The Super Sibs program provides support, peer connections, and developmentally appropriate activities for siblings of children with HIE to help them celebrate their strengths and roles within their families.



SUPPORTSPOT BY CHILD LIFE ON CALL

Free for HIE families, this app offers expert guidance, coping tools, and tailored resources to help the whole family navigate the emotional and developmental challenges of HIE.

ADDITIONAL SUPPORT & EDUCATIONAL RESOURCES

CLICK EACH FOR ACCESS



COMPREHENSIVE ONLINE SUPPORT NETWORK

We host over 100 age, location, outcome, demographic, and topic-focused support groups found on Facebook and aligned with our Community Guidelines to ensure a safe, consistent experience.



MEDICAL ADVISORY BOARD Q&As

Features medical providers from various specialties who provide relevant insights into the different ranges, impacts, and outcomes of HIE as well as clinical study and research updates.



HIE PEER PERSPECTIVE SERIES

Features experienced HIE parents and legal guardians who offer guidance, comfort, and support by sharing their insights and experiences with the diagnosis across all ranges, impacts, and outcomes.



CHILD LIFE Q&As

Features certified child life specialists as they offer expert insights, practical advice, and support and educational resources to support the whole family in the journey with HIE



CLINICAL TRIAL & RESEARCH HUB

Gathers resources reviewed by our Medical Advisory Board on participating in research and exploring treatments, medications, and therapies to improve families' quality of life.

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ONLINE COMMUNITY: SUPPORT FORUMS AND SUBGROUPS

[\[TINYURL.COM/HopeforHIEgroups\]](https://tinyurl.com/HopeforHIEgroups)

VISIT FOR LINKS AND DETAILS

MAIN SUPPORT FORUMS & GROUPS

Parent Support Hub - Closed Group

Loss Support Main Group

HIE Open Support Group - Public Posts

Professional Networking Group

OUTCOME-BASED GROUPS

In Between in HIE

More Severe Outcomes

Loss Support Main Group

Loss Support: Neonatal

Loss Support: Childhood

Loss Support: Adulthood

Parenting after HIE Loss

RESEARCH GROUPS

Advocacy & Research

STAR Study Support

COOL PRIME Study

AGE GROUPS

New to HIE

10 and Older

SOAR Program - ages 13-17

Adults Living with HIE

TOPIC-BASED GROUPS

Autism

Communication & AAC

Complementary Health

Learning, Attention & Behavior

PTSD & Mental Health

Self-Care for Parents

After Hours

Pregnancy after HIE

Member Marketplace

Palliative & Hospice Care

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ONLINE COMMUNITY: SUPPORT FORUMS AND SUBGROUPS, CONTINUED...

[\[TINYURL.COM/HopeforHIEgroups\]](https://tinyurl.com/HopeforHIEgroups)

VISIT FOR LINKS AND DETAILS

DEMOGRAPHIC-BASED GROUPS

Pride Parents
US Military Families
Extended Family Support
Loss Support: Extended Family
Foster & Adoptive Parents
HIE Dads
Twins
BIPOC
Acquired in Childhood
Single Parents
SuperSibs: Sibling Support

LANGUAGE-BASED GROUPS

Arabic-Speaking
French-Speaking
Spanish-Speaking
Hebrew-Speaking
Portuguese-Speaking

GLOBAL LOCATION GROUPS

Africa
Australia
Canada
Caribbean
Germany
India
Indonesia
Ireland
Israel
Malaysia
Mexico
Middle East
New Zealand
Nordic Countries
Pakistan
Philippines
Scotland
Singapore
South Africa
United Kingdom

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ONLINE COMMUNITY: SUPPORT FORUMS AND SUBGROUPS, CONTINUED...

[\[TINYURL.COM/HopeforHIEgroups\]](https://tinyurl.com/HopeforHIEgroups)

VISIT FOR LINKS AND DETAILS

US-BASED GROUPS

Alabama	Maryland	Pennsylvania
Alaska	Massachusetts	Puerto Rico
Arizona	Michigan	Rhode Island
Arkansas	Minnesota	South Carolina
California	Mississippi	South Dakota
Colorado	Missouri	Tennessee
Connecticut	Montana	Texas
Delaware	Nebraska	Utah
Florida	Nevada	Vermont
Georgia	New Hampshire	Virginia
Hawaii	New Jersey	Washington State
Idaho	New Mexico	West Virginia
Illinois	New York	Wisconsin
Indiana	North Carolina	Wyoming
Kansas	North Dakota	New England
Kentucky	Oklahoma	Chicago
Louisiana	Ohio	Louisiana
Maine	Oregon	

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