



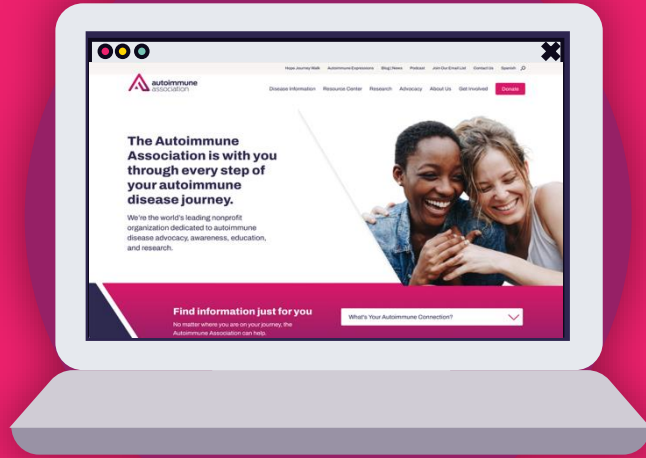
autoimmune
association

Support Group in a Box

A scalable infrastructure for structured, peer-led support

Presentation for: National Health Council

July 30, 2026

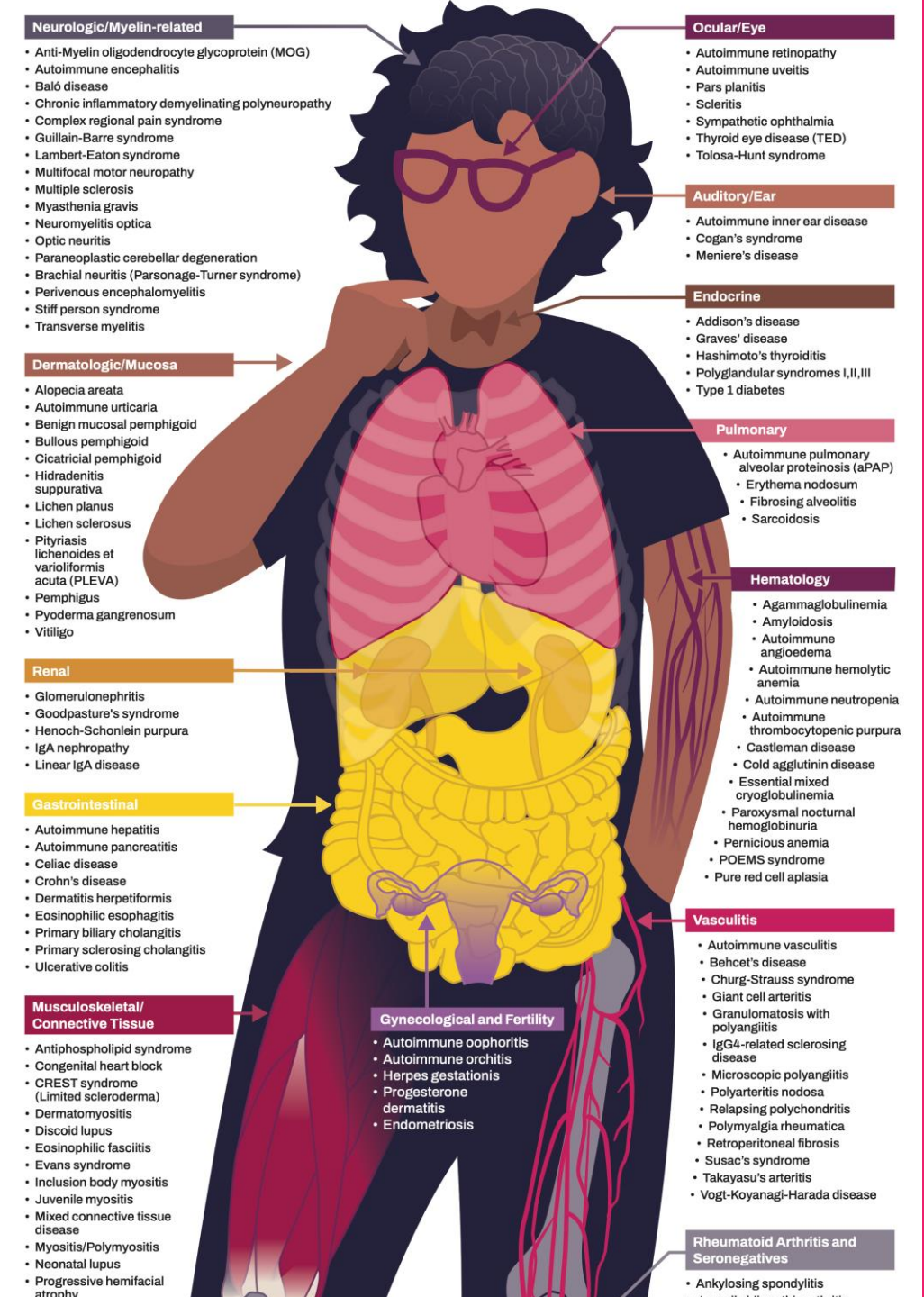


The **Autoimmune Association** is the world's leading nonprofit organization dedicated to Autoimmune **Awareness, Advocacy, Education, and Research.**



Autoimmune 101

- ✓ 50 million people in the US
- ✓ 80% are women
- ✓ 140 plus diseases
- ✓ 8-12% increase annually
- ✓ 4.5 years is the average journey to diagnosis
- ✓ 0 known cures



Association Goals

- ✓ Programs that evolve from patient engagement
- ✓ Inclusive voices that inform the process
- ✓ Practical, low-burden solutions that underscore the realities of today's healthcare environment



EMPOWERMENT

EDUCATION

SELF-ADVOCACY

Listening Sessions

- ✓ Online engagement with rural, lesser-served, Native, males, LGBTQ and others
- ✓ Series is ongoing and continues to highlight profound barriers and access to care
- ✓ Mental health issues continue to be listed as a primary concern
- ✓ Fewer resources for meaningful engagement



What we heard

- ✓ A consistent theme was having symptoms dismissed, minimized, or attributed to the demands of everyday life
- ✓ Patients wanted opportunities to share experiences and identify common challenges with people they trusted
- ✓ Feedback revealed the need for a culturally responsive, guided resource that communities could use on their own



We LISTEN



We RESPOND

Patient centered priorities

- ✓ Evolved comprehensively from patient feedback and engagement
- ✓ Framework is designed for maximum flexibility and user ease
- ✓ Core premise is to leverage the support from lived experience



What Support Group In a Box IS

- ✓ A structured, peer-led support framework
- ✓ A flexible series of ten guided sessions
- ✓ A practical toolkit for starting and facilitating “a group
- ✓ A psychologically safe space for sharing lived experience
- ✓ A way to build connection, resilience, and self-advocacy
- ✓ An adaptable model for different communities and settings



What Support Group In a Box **IS NOT**

- ✓ It is not therapy
- ✓ It is not medical, psychiatric, or mental-health treatment
- ✓ It is not a crisis-intervention service
- ✓ It is not a place for diagnosing conditions, recommending treatments, or telling another participant what medical decision to make
- ✓ It is not disease-specific

Designed to be **FLEXIBLE**

- ✓ 10 section prompts
- ✓ 10 prompts per section
- ✓ Guided questions reflect patient reported concerns
- ✓ Iterative design process helped refine the framework



Iterative, diverse pilots

- ✓ Two in lesser-served areas, two with young adults
- ✓ Feedback informed the overall topics
- ✓ Baked in the flexibility for patients to adjust questions as they see appropriate
- ✓ Pilot was both online and in person



Complete, ready to use toolkit

- ✓ Final version professionally reviewed for clarity, safety, and appropriate peer-support boundaries
- ✓ Oversight included analysis of all tool kit components designed for user safety, ease of use



Supporting the questions

- ✓ **Facilitator guides** with suggested language, pacing, boundaries, and tips for managing discussion
- ✓ **Participant materials** that support reflection, preparation, and continued engagement
- ✓ **Worksheets and templates** that make sessions easier to organize and lead
- ✓ **Resource and referral lists** for needs that extend beyond the scope of peer support
- ✓ **Training and orientation materials** to build facilitator confidence and consistency



Topics

- ✓ Telling Your Story is fundamental
- ✓ Self empowerment is at the heart of all the session
- ✓ Prompts designed for information on local healthcare system
- ✓ Shared community helps navigate support



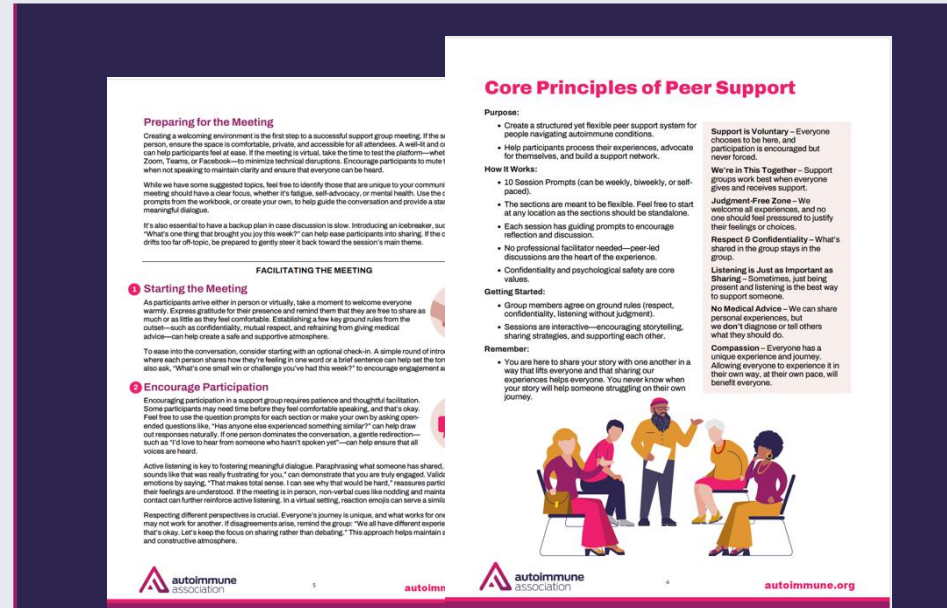
User driven design



- ✓ Designed to fit within a typical support group meeting
- ✓ Suggested timing for each section and activity
- ✓ Facilitators can shorten or augment based on participant needs
- ✓ Modules can be completed in one session or divided up

Who is it designed to help

User	Need	How it Helps
New leader	Does not know where to begin	Provides a step-by-step structure
Existing leader	Needs stronger facilitation skills	Offers targeted modules and tools
Organization	Wants consistency across groups	Provides a common framework
Community partner	Needs adaptable materials	Offers ready-to-use resources



We continue to iterate the tool kit based on ongoing
EVALUATION that **informs the future**

Where we go from here

- ✓ Separate or adapted version for young people
- ✓ Question refinements to reflect ongoing feedback
- ✓ Overhaul to reduce the total number of questions per prompt
- ✓ Video series to enable facilitator confidence
- ✓ Specific guidance on health insurance



Create Your Community



SUPPORT GROUP IN A BOX

A structured, peer-led approach to help patients navigate and share their autoimmune journey.

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BACKGROUND



During a series of listening sessions held over two years, patients reported feeling isolated and unheard, particularly in communities with limited access to care. While peer support is known to improve resilience and engagement, many patients lack the tools to create safe, effective groups.



We developed Support Group in a Box (SGIAB) in response to this patient-defined need as a structured, accessible framework that enables individuals to build meaningful peer connections without requiring professional facilitation.

GOALS



SGIAB was designed to assess whether a structured, peer-led model could safely and effectively support patients in building connection, sharing lived experience, and strengthening self-advocacy across diverse populations and settings, particularly those traditionally underserved by conventional support structures.

METHODS

SGIAB is a modular, peer-led toolkit consisting of **10 guided sessions**, each with **10 structured discussion prompts** built around topics identified by patients, including navigating care, fatigue, and self-advocacy.

The model includes a **facilitator guide** emphasizing psychological safety and clear boundaries, along with **journaling prompts** and **virtual meeting support**.



A pilot was conducted across four sites with facilitator-led cohorts; one site had a youth-focused implementation in a high school setting:



Qualitative feedback was collected after each session to iteratively refine the framework.

RESULTS

The pilot demonstrated strong engagement and emotional safety across all four sites, including during discussions of high-stakes topics such as mental health and patient advocacy. Structured prompts supported balanced participation and meaningful sharing. Participants reported reduced isolation and increased connection. The bond formed in at least one cohort was strong enough that participants independently organized ongoing monthly virtual check-ins following the conclusion of the pilot.

Participant feedback reflected meaningful impact:

"If you find connection, it can be freeing."

"It helped build focus and drive."

"Opened my eyes and mindset. Made me more aware."

"Meeting others and talking openly has been great."

The model also demonstrated notable adaptability. In one youth-focused site, a high school student living with chronic illness independently translated the SGIAB framework into a visual comic book format to increase accessibility and relevance for her peers

The adaptation, developed collaboratively with a student illustrator, is being implemented as a tool for a faculty professional development session, with support from school administration, demonstrating the model's potential to extend beyond patient communities into educational settings.



CONCLUSIONS

SGIAB demonstrates that **structured, peer-led support can effectively foster connection, resilience, and self-advocacy** without requiring professional facilitation.

The model is **scalable and adaptable across settings, populations, and formats**, as evidenced by its uptake across four pilot sites and an emergent youth adaptation.

Next steps:

- Broader dissemination
- Development of a Spanish-language version
- Formal youth-specific adaptations
- Rigorous evaluation of psychosocial and engagement outcomes.

Thank you,
National
Health Council





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Thank You!

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