SPONSORSHIP PACKET FALL 2023
No Aggregation Without Representation

SPONSOR
Does your organization support collective digital rights for patient communities? Sponsors help us to support our mission and increase our capacity.

PROGRAMS & IMPACT
Learn about The Light Collective’s Philosophy and programs.

INDIVIDUAL DONOR
Survivor, family member, or supporter? Your individual contribution can support the fight for your rights.

MEMBERSHIP OPTIONS
Engage in The Light Collective’s work in a meaningful and fulfilling way by becoming a member.

https://lightcollective.org
@BeLikeLight
Our leadership, board, and coalition all are comprised of diverse patient leaders representing a wide range of health conditions, communities, and organizations, from cancer to lupus to kidney disease.
GOAL:
GROW TO 60 PATIENT-LED MEMBER ORGANIZATIONS BY 2024
the problem

People with health challenges increasingly seek information and support from their peers on social media, as well as from a range of health apps, websites, and online technologies.

The growth and widespread utilization of online technologies by patients both illuminates and fills critical gaps in the formal healthcare system, but there are important ways in which engagement online puts people at risk of privacy violations, exploitation, misinformation, and other serious harms. Patients lack basic digital rights.

OUR MISSION STATEMENT

Our mission is to advance the collective rights, interests, and voices of patient communities in health technology.

OUR VISION

Our vision is a world in which patients and patient communities using health technologies, especially those who have been historically excluded and exploited, have access to the information and support they need, are safe from exploitation and harm, and have the right to decide how their health information is used.

We seek a future in which patients can engage safely online while navigating their health journeys, and where the role of patients in governing their data, developing research questions, and identifying important outcomes is recognized and supported on equal footing with technology companies and research and clinical partners.

AREAS OF FOCUS

Community Engagement
The Light Collective is dedicated to community-driven approaches to building digital rights. We organize coalitions of patient advocacy organizations which convene bi-weekly to share ideas, develop strategies, and take action for tackling shared problems around digital rights.

Education & Awareness
We provide trainings, webinars, convenings, and resources to grassroots organizations and individuals on:
- Online safety and digital rights;
- Fair partnerships with tech, research, and clinical partners; and,
- Best practices around peer support.

Advocacy & Policy
Policy plays a key role in securing patient digital rights. The Light Collective works with diverse actors to build policies that positively impact patient communities globally.
PROGRAMS & IMPACT

An innovative approach to patient digital rights is necessary for transformational change in health tech.

Security Research: Peer-Reviewed Publications
After Cambridge Analytica, our research and advocacy led to a Congressional Inquiry on the privacy of health-focused Facebook groups. In 2022, our peer-reviewed study resulted in health breach notifications affecting 61 million patients. By December of 2022, this research also led to an unprecedented ban of online tracking technologies by HHS for HIPAA-covered entities. TLC continues to engage in research to shed light on the ways in which patient privacy is put at risk by health technologies and identify ways to mitigate these risks.

Events: Light the Way Summit
The Light the Way Summit is an annual multi-day meeting for individuals and organizations interested in building digital rights and community governance for patient communities. TLC also organizes and participates in regular Town Halls and other virtual events and is developing an annual in-person training program.

Collective Digital Rights: Strategy Playbook
TLC has created a guide to help patient advocacy organizations negotiate fair partnerships with health technology companies and continues to build resources for patient communities to interact meaningfully and ethically with technology, research, and clinical partners.

Public Speaking: Education & Advocacy
The Light Collective team and Board members engage frequently in speaking engagements to teach about the digital rights landscape, advocate for community governance, and inform on practices. We have spoken at Defcon, National Health Policy Conference, Stanford MedX, and many other conferences, and taught classes at Stanford, Duke, and Weill Cornell Medical School.

Peer Support Research: Publication
The Light Collective has studied how and why people with cancer/at high risk of cancer use online peer support. In 2023, TLC published an article in the Journal of Patient-Centered Research and is currently working on new research in this area.

IMPACT AT A GLANCE

Organizational Coalition Members, representing 40,000 patients

28

Organizations completed TLC’s Digital Rights Training

83

Webinars & Community Town Halls

>40

Public Speaking Engagements

4

Peer Reviewed Publications

4

Public Comments on Patient Digital Rights

COMING SOON

- Tracker Tool For Members
- Expanded research on illegal use of online tracking technologies
- Expanding coalition by 200%
- Full Resource Library
- Patient-driven needs assessment for AI
# Become a Member of The Light Collective

<table>
<thead>
<tr>
<th>Membership Level</th>
<th>Seats</th>
<th>Description</th>
<th>Annual Cost</th>
<th>Monthly Cost</th>
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<tbody>
<tr>
<td><strong>Ambassador Membership Level (6-8 People)</strong></td>
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<td>At this level you will receive up to 8 seats for the following:</td>
<td>$3,000</td>
<td>$250/month</td>
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<td>• Basic Cybersecurity Training</td>
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<td>• Scanner Tool For Cross-Site Tracking</td>
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<td>• Access To Our Full Resource Library</td>
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<td><strong>Advocate Membership Level (4 People)</strong></td>
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<td>At this level you will receive up to 4 seats for the following:</td>
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<td>• Basic Cybersecurity Training</td>
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<td><strong>Ally Membership Level (2 People)</strong></td>
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<td>At this level you will receive up to 2 seats for the following:</td>
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<td>• Basic Cybersecurity Training</td>
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<td>• Scanner Tool For Cross-Site Tracking</td>
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<td><strong>Associate Membership Level (1 Person)</strong></td>
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<td>At this level you will receive up to 2 seats for the following:</td>
<td>$300</td>
<td>$25/month</td>
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<td>• Basic Cybersecurity Training</td>
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For questions on membership: contact@lightcollective.org
Corporate Sponsors

Our Impact is Global
Corporate sponsors make a huge difference for The Light Collective. The organizational sponsorship levels provide general operating, program and sustainability support for this work. All corporate sponsors will be highlighted on The Light Collective website. Global companies are welcome to support this work.

Organization
$50,000
- Supports the overall mission, vision and sustainability of The Light Collective’s new and innovative approaches to establishing and protecting patient digital rights.

Community
$25,000
- Supports participation of 4 patients in The Light Collective’s annual 4 day in-person data rights and community governance training.

Patient
$15,000
- Supports one patient representative to serve on a governance board at Fair Market Value for their time:
- https://nationalhealthcouncil.org/fair-market-value-calculator/

Awareness
$7,000
- Supports two Light Collective representatives to participate in a national conference like Defcon or the National Health Policy Conference.

We need your help to support the fight for digital rights for patient communities.

Get in Touch with Us
- Email: andrea@lightcollective.org
- Website: https://lightcollective.org
WHY SPONSOR US

WHY SPONSOR US

The Light Collective is the only patient-led nonprofit that is driving independent governance of health technology. We want to make sure that patient data is protected on the digital landscape through education and policy reform.

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Event Sponsorship

**The Light Collective**

**LIGHT THE WAY SUMMIT**

“A global approach to digital rights for patient communities”

**HYBRID EVENT**

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**PLATINUM**

$100,000

- Speaking address to the audience (3-5min)
- Financial Assistance Support for 4 Patient Attendees
- 6 Registrations to the Light The Way Conference

- Includes Print Perks-

**GOLD**

$50,000

- Financial Assistance Support for 3 patient attendees
- 5 Registrations to the Light The Way Conference
- Banner with logo printed (6’X4’)

- Includes Print Perks-

**SILVER**

$5,000

- Financial Assistance Support for 2 patient attendees
- 4 Registrations to the Light The Way Conference

- Includes Print Perks-

**BRONZE**

$2,500

- 2 registrations to the Light The Way Conference
- Highlighted Event Recognition
- Social media recognition
- Logo recognition on event flyers
- Logo listed on website as a 'Bronze' Sponsor

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- Print Perks -
Health Sites Let Ads Track Visitors Without Telling Them
by Lily Hay Newman

Privacy policies didn't tell the whole story about third-party tools gathering personal information from the sites of medical and genetic-testing companies. This story broke our research in February 2022.

To become an Amazon Clinic patient, first you sign away some privacy
by Geoffrey Fowler

You agreed to what? The 'HIPAA authorization' for Amazon's new low-cost clinic offers the tech giant more control over your health data. The Light Collective served as a source and advised during the journalist's investigation.

A cyberattack on one hospital can disrupt an entire network of medical providers
by Jenna McLaughlin

You agreed to what? The 'HIPAA authorization' for Amazon's new low-cost clinic offers the tech giant more control over your health data. The Light Collective served as a source and advised during the journalist's investigation.

Patients Advance Meta Lawsuit Over Collecting Health Information

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