



## Patient Advocacy Town Hall - Session Summary

April 14<sup>th</sup>, 2021

### Creating Community through the Cancer Diagnosis:

#### Stupid Cancer:

- Stupid Cancer creates spaces for adolescents and young adults (AYAs) to come together and connect about the issues they are facing.
  - [Webinars](#) and Discussion Series are interactive and educational sessions led by subject matter experts on issues important to the AYA community.
  - Stupid Cancer [Meetups](#) are social gatherings that bring together the community online or in-person to connect with other patients, survivors, caregivers, and professionals who get it.
  - [Stupid Cancer Stories](#) is a multimedia platform where community members can share their experience and connect with peers through the power of storytelling.
  - Stupid Cancer's signature program, CancerCon, is an annual conference that brings together hundreds of patients, survivors, caregivers, and professionals for a weekend of information, education, and social activity.
    - [Digital CancerCon 2021: June 11-13th](#)

### Creating Community in Underserved Populations:

#### The Leukemia & Lymphoma Society (LLS):

- [Myeloma Link](#) is a program intended to increase access to education about and treatment for myeloma in African American communities. Community members are provided information and education through a number of vehicles, including awareness presentations at churches, libraries, community and senior centers, and participation in health fairs. Primary care providers at Federally Qualified and Community Health Centers are educated about the disease, including the symptoms and treatments. This program is currently operating in 13 cities across the country, and, since its inception in 2017, has reached more than 27,000 patients through over 200 outreach activities for patients, healthcare providers, and the general community.
- Engagement with the Latinx Community:
  - With the help of multimedia groups that specifically work in Latinx communities, LLS presented information for blood cancer patients via Facebook live, radio, and television. All of the information was presented in Spanish.
  - Have worked with the Mexican Consulate and groups of community health workers and promotores, the lay Hispanic/Latino community members who receive specialized training to provide basic health education in the community without being a professional health care worker.
  - Recently upgraded Spanish language website pages.

#### Cancer Support Community (CSC):

- [Activating Change Through Intentional Voices for Equity \(ACTIVE\) Task Force](#): An examination of CSC's policies, practices, mission, and culture to embed an anti-racism lens, through the work of the following areas:

- Strategic Plan, Mission, Vision
- HR Functions, Organizational Culture and Values
- Health Equity in Oncology Data
- Diversity Initiatives Steering Committee
- [Work on Tribal Lands and Navajo Nation:](#)
  - The first, and only, cancer treatment facility was launched on the Navajo Nation about one year ago. CSC provides social and emotional support services for individuals receiving cancer treatment there.

### Stupid Cancer:

- Stupid Cancer's primary focus is building and supporting the AYA community. The AYA oncology field is in its infancy, only having been recognized and solidified within the past decade or so. Because of this, clinical research into the biological differences in AYA tumors and the psychosocial experience of a young person has a long way to go. Simply put, the AYA cancer community is the most underserved patient population by age. Stupid Cancer also recognizes that within the underserved AYA population, there is another divide along racial, economic, and sexual identity lines. Stupid Cancer provides spaces for each of these unique populations of AYAs to come together and explore their shared experiences while working to better understand those challenges so they can continue to address them both internally and on a broader systemic level.

### Unique Programs & Resources:

#### Society for Immunotherapy of Cancer (SITC):

- SITC is focused on immunotherapy education and resources for healthcare professionals to help drive the field of oncology forward.
  - SITC's effort culminate in an [Annual Meeting](#) every November where over 5,000 individuals gather to discuss the latest scientific and clinical advances concerning cancer immunotherapy, all with the goal to further advance science to improve treatment safety and efficacy.
    - 36<sup>th</sup> Annual Meeting & Pre-Conference Programs (SITC2021): November 10-14, 2021
  - SITC offers an online education platform called [SITC ConnectED](#). The ConnectED Resource Library contains thousands of entries with education for all levels, including dedicated courses, such as the new [Certificate in Cancer Immunotherapy program](#), and recordings and materials from past educational meetings, such as the [Advances in Cancer Immunotherapy \(ACI\) series](#) and webinars for the [Cancer Immunotherapy Guideline Program](#).
- [SITC ConnectED](#) offers online resources for cancer patients, survivors, caregivers, and advocates. This platform has a vast array of resources, including recorded courses, webinars, workshops, as well as written materials such as pamphlets. There are materials for virtually any audience and any level of scientific knowledge. For patients specifically, SITC offers [Patient Resource Guides](#) which are print materials that serve as great resources for patients looking for information concerning cancer immunotherapy and how it relates to their disease. These guides are also a good resource for healthcare professionals looking to provide something for their patients. They provide a good overview of the science behind the treatment, any adverse events, and many of the guides have an attached online course that you can take to help solidify the content.
- SITC is currently working to form a Survivorship Expert Panel, which is an effort to listen to patients, survivors, and advocates, hear what kind of resources would be helpful to have based on their experiences, and make sure the patient voice is heard throughout all of SITC's efforts.

- SITC is also working behind the scenes to ensure optimal patient care. The policy department is working to develop immunotherapy-centric quality measures to help guide safe and effective clinical practice. These measures also ensure proper reimbursement for these therapies through Medicare and Medicaid.

Patient Access Network (PAN) Foundation:

- The PAN Foundation is one of nine national patient assistance programs providing financial assistance to cover out-of-pocket costs for prescription medications. PAN Foundation currently operates about [70 different patient assistance programs](#) for various diseases and conditions. Around 20 of those programs are specific to oncology. PAN Foundation provides grants to patients to cover most, if not all, out-of-pocket costs, such as copays, deductibles, and co-insurance, for their prescription medications. All of these assistance programs, as well as eligibility guidelines and lists of medications in broad formularies, can be found at [PANFoundation.org](#).
  - Pharmacists and pharmacy staff can log onto PAN Foundation's [Pharmacy Portal](#) directly from their homepage. Visitors will be asked for certain information about the patient, and within minutes they will be told whether their patient is eligible for a grant. From that point on, patients can access their medications, and pharmacy staff can submit claims electronically to PAN. Patients can also be enrolled in the waitlist to be notified as soon as additional funding is available.
- PAN Foundation also offers a [Transportation Program](#) to make sure Medicare patients can adhere and stay on treatment. \$500 in assistance is offered per year, which can cover costs of taxis and ride shares, public transportation, and parking.
- PAN Foundation is also creating awareness around a federal program called [Extra Help](#), or the Low Income Subsidy Program. This program allows Medicare beneficiaries to save up to 85% or more in out-of-pocket costs for their prescription medications. PAN Foundation now offers an education hub and eligibility checker for this program.

The Leukemia & Lymphoma Society (LLS):

- [Clinical Trial Support Center \(CTSC\)](#): Clinical trial nurse navigators are available to increase patients' opportunities for clinical trial participation by facilitating informed decision-making and minimizing logistical barriers for the patient and their family. Patients can be referred by one of LLS's Information Specialists, fill out an online referral form, or be referred by their physician. There is currently a referral system set up with ASH physicians as well as VA doctors. The nurses can and do:
  - Educate patients and gather detailed information about the patient's health status, genomic markers, prior treatment, treatment goals, and support system.
  - Speak to patients' physician, clinical trial sites, and trial sponsor to gather information needed to conduct the most tailored trial search.
  - Work with the IRC to help patients and their families overcome barriers to enrollment, including financial and travel challenges.
  - Provide patients with an individualized, patient-friendly, refined list of appropriate clinical trials to discuss with their health care team.
  - Engage in follow-up throughout the process, even when a patient is on a trial or is post-trial – the nurses often help people over a number of years.
- [1:1 Nutrition Consultations](#): LLS provides PearlPoint Nutrition Services to patients and caregivers of all cancer types, offering free nutrition education and consultations. LLS's registered dietician has expertise in oncology nutrition and provides free one-on-one consultations by phone or email.

- The [LLS Health Manager App](#) allows patients or their caregivers to manage their health by tracking side effects, medication, food and hydration, questions for their doctor, grocery lists, and more. The information can be exported into a calendar format and shared with the health care provider.
- [LLS Patient Community](#): This program is specifically for blood cancer patients, caregiver, supporters, and health care providers. It is monitored on a daily basis by staff, and patient issues are followed up by an IRC staff when indicated. There are also various groups for BIPOC and LGBTQA.
- [The Trish Greene Back to School Program for Children with Cancer](#) offers free information and materials to parents and educators. The program was developed to encourage communication among parents, young patients, healthcare professionals, and school personnel to assure children a smooth transition from active treatment to back to school.
- [Staying Connected: Facilitating the Learning Experience During and After Cancer Treatment](#) is an online continuing education program for teachers, school nurses, social workers, school counselors, and other school and college personnel focused on the needs of children, adolescents and young adults (AYAs) who have survived or are being treated for any type of cancer. The program provides information on cancers that affect children and AYAs, education and psychosocial challenges for survivors throughout their education, laws that protect childhood/AYA survivors' rights, strategies to help meet the students' needs, and resources to support schools and families.
- LLS has close to [250 educational resources](#) patients and caregivers can order including workbooks specifically focused on different populations such as young adults, pediatrics, and caregivers. Including the Health Manager app, LLS also has a coloring app for children that includes pictures to help them understand and deal with a cancer diagnosis.

### **Finding Financial & Emotional Support:**

#### CancerCare:

- CancerCare's [Online Helping Hand](#) is a searchable, online database of financial and practical assistance available for people with cancer. This comprehensive online tool features up-to-date contact information and descriptions for hundreds of national and regional organizations offering financial help to people with cancer.
- Additional Financial Resources:
  - Federal & State Programs
  - Government Assistance Programs
    - Department of Health & Human Services (HHS)
    - Administration on Aging
    - Social Security Administration (SSA)
    - Centers for Medicare & Medicaid Services (CMS)
  - Pharmaceutical Patient Assistance Programs
  - Non-Profit Organizations – Copay Relief Programs
  - Patient Advocacy/Cancer Organizations – Copay Relief Programs
- CancerCare helps support patients from the first day of diagnosis through the end of treatment, as well as those who are bereaved. CancerCare staff provide support using their HOPA-line, individual counseling, support groups, community programs and more. They offer support to patients in treatment, post-treatment, caregivers, and those who are bereaved. [Counseling](#) is the core of what CancerCare does. Their oncology social workers can provide cancer-focused support, help reduce feelings of anxiety and distress, help increase feelings of hope and empowerment, assist with learning new ways of coping, help provide communication between the patient, loved ones, and the medical team, provide practical information about treatment, and provide resources in the

community. Counseling is currently available over the phone and virtually for residents of New York and New Jersey.

- [Case Management Services](#): Oncology social workers offer individualized and professional guidance to help people living with cancer, post-treatment survivors, and caregivers address barriers to care. This services is available over the phone.
- [Live Support Groups](#): Support groups are led by oncology social workers via videoconferencing and over the phone for NY and NJ residents. For those that live outside of NY or NJ, oncology social workers can help locate a local support group in the patient’s community.
- [Online Support Groups](#): Password-protected online group led by an oncology social worker in a message board format. There is a registration process, but once approved, individuals can post 24 hours a day, 7 days a week. Many individuals like to use these message boards to share their stories and connect with others in a safe and private space.
- [Coping Circle Community Programs](#): New, specialized programs that are designed to provide education and connection to those impacted by cancer. Previous programming includes yoga classes, wellness classes, cooking classes, game nights, educational workshops, book clubs, social meetups, and more.
- [Connect Education Workshops](#) offer the latest information from leading oncology experts over the phone and online.

#### Cancer Support Community (CSC):

- CSC’s affiliate network consists of 175 locations in 50 markets around the United States, as well as several international locations. These locations provide \$50 million in free services and have over 500,000 visits by patients and their loved ones every year.
- CSC also offers a [Cancer Support Helpline](#) for those who are not visiting an affiliate or have a specific question they need support on. Due to the increasing need following COVID-19, the helpline is now open 7 days a week and receives 40,000 calls each year. Helpline workers can connect patients, survivors, and caregiver to local and national resources, provide short-term cancer coping assistance, connect callers with short-term housing, help with treatment decision making, and provide financial navigation.

#### PAN Foundation:

- [FundFinder](#) is a unique app for patients and providers that not only alerts patients and providers when financial assistance is available, but also connects individuals with patient groups that can provide needed support. The app tracks the available funds status of 200 programs in one convenient place, and anyone can access it for free. Once signed up, patients can get instant alerts by email or text message when financial assistance is available. The app also recently added many patient advocacy organizations, so that users can connect with groups who provide education and support.
- [Alliance Partner Model](#): PAN Foundation has aligned with national patient advocacy organizations who are positioned to provide follow-up education and supportive care to patients.
- Social Media: Platforms such as [Facebook](#), [Twitter](#), [Instagram](#), and [LinkedIn](#) offer community to patients, their caregivers, and providers. Through these platforms, PAN Foundation is able to disseminate important information about their programs.

**For more information about the services these organizations offer, please contact:**

- CancerCare: [ewojcik@cancercares.org](mailto:ewojcik@cancercares.org)
- Cancer Support Community: [action@cancersupportcommunity.org](mailto:action@cancersupportcommunity.org)
- The Leukemia & Lymphoma Society: [karen.demairo@LLS.org](mailto:karen.demairo@LLS.org)
- PAN Foundation: [mpawlowski@panfoundation.org](mailto:mpawlowski@panfoundation.org)
- SITC: [policy@sitcancer.org](mailto:policy@sitcancer.org)
- Stupid Cancer: [asilberman@stupidcancer.org](mailto:asilberman@stupidcancer.org)