

# A Lion in the House

a film by Steven Bognar and Julia Reichert

COMMUNITY ENGAGEMENT CAMPAIGN



## A LION IN THE HOUSE Community Engagement Campaign

# Campaign Tool Kit: Working with National Partners

The LION IN THE HOUSE Tool Kit was created to guide public television stations, organizations and the community to support A LION IN THE HOUSE outreach activities in collaboration with national partners: American Academy of Pediatrics (AAP), American Cancer Society (ACS), Association of Oncology Social Work (AOSW), Association of Pediatric Oncology Nurses (APON), Centers for Disease Control and Prevention (CDC), Children's Cause for Cancer Advocacy (CCCA), CureSearch, Gilda's Club Worldwide, Health Ministries Association (HMA), Hope Street Kids, Intercultural Cancer Council (ICC), Lance Armstrong Foundation (LAF), Leukemia & Lymphoma Society (LLS), National Association of Social Workers (NASW), National Cancer Institute (NCI), National Hospice and Palliative Care Organization (NHPCO), Oncology Nursing Society (ONS), PADRES Contra El Cáncer.

**Get involved at [www.itvs.org/outreach/lioninthehouse](http://www.itvs.org/outreach/lioninthehouse).**



## American Academy of Pediatrics (AAP)

[www.aap.org](http://www.aap.org)

The American Academy of Pediatrics (AAP) is an organization of 60,000 pediatricians committed to the attainment of optimal physical, mental and social health and well-being for all infants, children, adolescents and young adults. The AAP also houses the National Center of Medical Home Initiatives for Children with Special Needs.

## National Center of Medical Home Initiatives for Children with Special Needs at the American Academy of Pediatrics

[www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)

The National Center promotes a model of care for special-needs children called a “medical home.” In a medical home, a pediatric clinician works in partnership with the family/patient to assure that the medical and nonmedical needs of the patient are met. The care plan combines palliative care and life-prolonging care for children and youth living with life-threatening or terminal conditions and their families. The Medical Home Initiative is supported by the Health Resources and Services Administration and its Bureau of Maternal and Child Health and provides the potential to extend supportive services to childhood cancer patients and survivors.

### Partnering with AAP Chapters and Medical Home

The AAP has 60,000 members in 59 chapters in the United States. Locate your state’s chapter office at <http://www.aap.org/member/chapters/chaplist.cfm>. See “Tips for Working Effectively with AAP Chapters” on page 4. AAP chapter members can provide support to the LION IN THE HOUSE campaign in the following ways:

- Provide expertise and serve as spokespeople on medical issues and focus areas.
- Provide linkages to patients and families who might like to be involved.

To find out about events and activities happening in your state that will help improve access to medical homes for children and youth with special health care needs, go to: <http://www.medicalhomeinfo.org/states/index.html>. These pages also provide state work plans and activities that might support your A LION IN THE HOUSE campaign.

## *American Academy of Pediatrics Continued*

### Resources

- Compassionate and culturally competent care resources  
<http://www.medicalhomeinfo.org/tools/compassion.html>
- Tools and information for families and providers on palliative care  
<http://www.medicalhomeinfo.org/resources/palliative.html>
- Advocacy and spokesperson tips and background materials for families and practitioners on issues of special-needs children  
<http://www.medicalhomeinfo.org/health/advocacy.html>
- Tools and training materials to assess and implement medical home  
<http://www.medicalhomeinfo.org/tools/providerindex.html>

## Tips for Working Effectively with AAP Chapters

### Background Information on Chapters

Chapters are organized groups of pediatricians and other health care professionals working to implement AAP policy at the state and community levels and address the needs of their members. There are 59 chapters in the United States and seven chapters in Canada. The U.S. chapters are usually drawn along state lines, but two states with large populations (California and New York) constitute more than one chapter. In addition, two chapters serve pediatricians in the uniformed services (east and west, divided by the Mississippi River). Puerto Rico and the District of Columbia are also separate chapters.

Chapters provide advocacy, leadership, education and networking opportunities for AAP members. The AAP and its chapters have a unique partnership of autonomy and cooperation. Although required to maintain bylaws and see that these bylaws do not conflict with the AAP's and to elect officers (president and vice president) who are voting members of the AAP, chapters have complete organizational control over their activities. This autonomy gives chapters the freedom to address the needs and interests of their individual members.

### Partnering with AAP Chapters

Chapters are independently incorporated. They are separate entities from the national AAP. As such, chapters have control over their priorities and set their own agendas. When working with AAP chapters, it is helpful to keep the following in mind:

- Chapter leaders are *volunteers*. Chapter presidents and vice presidents are not paid for the work they do on behalf of children. They are often very busy individuals, currently in practice, and prefer to communicate via email. If you need a chapter leader to attend a meeting on a weekday, please keep in mind that canceling office hours cannot usually be done on short notice. Please allow sufficient lead-time if you want the participation of chapter leaders.
- When corresponding with chapter leaders, it helps to be *very clear and concise*. With limited free time in which to perform their chapter-officer duties, the briefer the better in terms of correspondence (whether electronic or by mail).
- It is recommended that a *copy of all letters or correspondence be sent to the chapter executive director (ED)*. Most chapters (55) have EDs, and since they are often the chief administrator in the chapter, it is helpful to copy them on all items that are sent to the chapter presidents and chapter vice presidents.
- If you want to learn more about a chapter or are interested in finding out more about how you/your project can interface with a chapter, request to attend an upcoming chapter meeting. The chapter ED will have those dates, times and locations for you.
- An executive committee or board governs every chapter. This governing body often does not meet more than monthly. If you need an official decision by the chapter, please keep this timeline in mind.

For more information about chapters, visit the Member Center on the AAP website (<http://www.aap.org>) and select "Chapters" or call 800-433-9016.

## American Cancer Society (ACS)

[www.cancer.org](http://www.cancer.org)

The American Cancer Society (ACS) is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer through research, education, advocacy and service. With more than two million volunteers nationwide, the ACS is one of the oldest and largest voluntary health agencies in the United States. The American Cancer Society, Inc., consists of the national Society, chartered Divisions throughout the country and more than 3,400 local Units.

### Partnering with ACS

You can locate ACS Divisions or Units near you at <http://www.cancer.org>. ACS staff and volunteers can provide support to local A LION IN THE HOUSE collaboratives in the following ways:

- Provide expertise and serve as spokespeople on medical issues and focus areas.
- Provide available resources for community engagement.

### Potential Community Engagement Activities

- Host a screening of A LION IN THE HOUSE module(s) for staff, volunteers and during professional education activities to build skills and awareness of issues of childhood cancer, survivorship, cancer health disparities and pediatric palliative care.
- Host A LION IN THE HOUSE viewings of the entire series with follow-up discussions.
- Engage ACS Colleges Against Cancer in the SurvivorAlert! project.

### Resources

- Cancer Information Specialists are available 24 hours a day/seven days a week/365 days a year at 800-ACS-2345. Translation services are also available.
- An extensive website located at <http://www.cancer.org> offers support and resources to patients and survivors. The site also has Spanish content.
  - Childhood cancer resources and information can be found at: [http://www.cancer.org/docroot/CRI/CRI\\_2\\_6x\\_Children\\_and\\_Cancer.asp](http://www.cancer.org/docroot/CRI/CRI_2_6x_Children_and_Cancer.asp)
  - Search for a pediatric cancer center in your area: [http://www.cancer.org/asp/search/ftc/ftc\\_global.asp?navToScreen=ftc\\_3](http://www.cancer.org/asp/search/ftc/ftc_global.asp?navToScreen=ftc_3)
  - The ACS provides a wide variety of print publications available to the public at: [http://www.cancer.org/docroot/pub/pub\\_0.asp](http://www.cancer.org/docroot/pub/pub_0.asp)
- Look Good ... Feel Better for Teens is a free program for teenage cancer patients 13 through 17 years old that helps them cope with the appearance-related side effects of cancer treatment. Visit <http://www.2bMe.org>.

## ***American Cancer Society Continued***

### **Resources Continued**

- The ACS provides college scholarships to more than 1,000 young adults each year. To learn about scholarships in each division, call 800-ACS-2345.
- Nationwide, the ACS sponsors camps that specialize in providing a fun experience for young cancer patients. Oncology doctors and nurses volunteer their time to provide medical attention to campers. All ACS Camps are accredited by the National Camping Association, which is considered the gold standard. To make these camps more accessible to all, many are available at low or no cost to the camper. Some have programs that include siblings of cancer patients.
- The ACS provides support for survivors and patients through a Cancer Survivors Network, an online support community for cancer patients and caregivers.

## Association of Oncology Social Work (AOSW)

[www.aosw.org](http://www.aosw.org)

The Association of Oncology Social Work (AOSW) provides a wide range of services directly to persons with cancer and their families, including counseling, support, education and resource identification. Its members connect persons diagnosed with cancer and their families with essential community, state, national and international resources. The AOSW represents more than 900 social workers worldwide practicing in hospitals, outpatient clinics, home care and hospice agencies, community wellness programs, patient advocacy organizations, and other settings as part of an oncology team. As advocates, the AOSW and its members are dedicated to increasing awareness about the social, emotional, educational and spiritual needs of cancer patients through conferences, research, writing, workshops and lectures.

### Partnering with the AOSW and Local Oncology Social Workers

The AOSW's regional directors can be found at <http://www.aosw.org/who/board.html>. They may be able to connect you to pediatric oncology social workers in your community or state. You can also contact them through your cancer centers. AOSW members can provide support to local collaboratives in the following ways:

- Provide expertise and serve as spokespeople on the psychosocial needs of childhood cancer patients and families and available local resources.
- Provide linkages to patients and families who might like to be involved.

### Community Engagement Activities

- Utilize A LION IN THE HOUSE module(s) and film as a teaching tool with school professionals.
- Feature A LION IN THE HOUSE module(s) and discussion guide at conferences and trainings for oncology teams, cancer support organizations and other providers of care for child cancer patients and families.
- Host a screening of A LION IN THE HOUSE module(s) for community leaders addressing how support can be strengthened for families whose children face life-threatening illness.
- Support survivor event planning and outreach in conjunction with the CDC SurvivorAlert! project.
- Utilize A LION IN THE HOUSE module(s) as a teaching tool focusing on addressing cancer health disparities.

## *Association of Oncology Social Work Continued*

### **Resources**

The AOSW website's publication page provides links for new resources and publications, several specific to pediatric cancers:  
<http://www.aosw.org/publications/publications.html>

## Association of Pediatric Oncology Nurses (APON)

[www.apon.org](http://www.apon.org)

The Association of Pediatric Oncology Nurses (APON) is the leading professional organization for registered nurses caring for children and adolescents with cancer and blood disorders and their families.

### Partnering with APON

With 2,300 members in 38 chapters in the United States and Canada, you can locate chapters near you at <http://www.apon.org>. Chapter members can provide support to local collaboratives in the following ways:

- Provide expertise and serve as spokespeople on medical issues and focus areas.
- Provide linkages to patients and families who might like to be involved.

### Community Engagement Activities

- Feature A LION IN THE HOUSE module(s) and discussion guide at conferences and trainings for oncology teams, cancer support organizations and other providers of care for child cancer patients and families.
- Host a screening of A LION IN THE HOUSE module(s) for community leaders addressing how support can be strengthened for families whose children face life-threatening illness.
- Support survivor event planning and outreach in conjunction with the CDC SurvivorAlert! project.
- Utilize A LION IN THE HOUSE module(s) as a teaching tool focusing on improved palliative, end-of-life and bereavement care.

### Resources

The APON publishes selected patient/family resource materials. For more information, visit the APON website at <http://www.apon.org>.

## Centers for Disease Control and Prevention (CDC) Cancer Prevention and Control

[www.cdc.gov/cancer/](http://www.cdc.gov/cancer/)

The Centers for Disease Control and Prevention (CDC) works closely with national organizations, state health agencies and other key groups to develop, implement and promote effective cancer prevention and control strategies, including initiatives in cancer survivorship. The CDC supports 61 comprehensive cancer control programs, including those in 49 states, the District of Columbia, five tribes and tribal organizations, and six U.S. Associated Pacific Islands/territories. In collaboration with the Lance Armstrong Foundation and other leaders in cancer survivorship, the CDC developed a National Action Plan for Cancer Survivorship in 2004.

### Partnering with State/Tribe/Territory Comprehensive Cancer Control Programs

Locate state cancer control partners at Cancer Control Planet, <http://cancerplanet.cancer.gov/index.html>. This site links to state health departments, the American Cancer Society and the National Cancer Institute's Cancer Information Service. These cancer control leaders can help connect your project with other resources, organizations and initiatives developed as part of your state's Cancer Plan. Your State Cancer Profile can be found at the same site. View your state's Cancer Plan at [www.cancerplan.org](http://www.cancerplan.org).

- The LION IN THE HOUSE CDC contact can also connect you with leaders involved in community/state partnerships surrounding childhood/young adult survivorship. Kentucky, Tennessee, Ohio, Texas and New Jersey are a few of the many states with programs engaged in this initiative.
- Your state cancer control planning group may be able to provide linkages to resources, partners and childhood/young adult cancer survivors and families who might like to be involved in the project.

### Community Engagement Activities

- Host a screening of A LION IN THE HOUSE in collaboration with state cancer control partners.
- Explore ways to utilize the film and outreach resources to support initiatives around survivorship, cancer health disparities and palliative care.
- Raise awareness of childhood and young adult cancer issues, such as services needed during treatment and community-based long-term follow-up clinics to key cancer and advocacy leaders in your area.

## *Centers for Disease Control and Prevention Continued*

### **Resources**

Several helpful resources on cancer survivorship can be found at <http://www.cdc.gov/cancer/survivorship/index.htm>, including:

- National Action Plan for Cancer Survivorship: Advancing Public Health Strategies
- Survive Cancer and Live brochure
- Services and resources for cancer survivors
- Link to the President's Cancer Panel publications:
  - "Living Beyond Cancer: Finding a New Balance"
  - "Voices of a Broken System: Real People, Real Problems"

## Children's Cause for Cancer Advocacy (CCCA)

[www.childrenscause.org](http://www.childrenscause.org)

The Children's Cause for Cancer Advocacy (CCCA) is a nonprofit organization that works as a national catalyst to stimulate drug discovery and development for childhood cancers, to expand resources for research and treatment, and to address the needs and concerns of survivors. The CCCA works with policymakers to advance basic and clinical research, health care, and services for childhood cancer patients, survivors and their families.

### Partnering with the CCCA

The CCCA supports efforts at the individual, community, institutional and national policy levels to effect change. Advocacy is necessary at all these points on the continuum if children with cancer and long-term survivors are to receive quality care and if childhood cancer is to be eradicated. The CCCA supports advocacy in the community by:

- Participating in dozens of national research and health care policy forums to ensure that policy outcomes take into account the needs of children.
- Working with Congress to increase cancer research funding and to ensure more efficient ways of developing and evaluating new anti-cancer therapies for children.
- Developing tools that educate providers about the unique needs of childhood cancer patients and survivors.
- Empowering patients, survivors and their families to advocate on behalf of themselves and others.

### Community Engagement Activities

Host a screening of A LION IN THE HOUSE module(s) for policymakers, community leaders and other change agents who can impact care and resources for families faced with childhood cancer.

### Resources

- Search for new treatments for childhood cancer and clinical trials at [http://www.childrenscause.org/resources/finding\\_clinical\\_trials.shtml](http://www.childrenscause.org/resources/finding_clinical_trials.shtml).
- The CCCA has developed an innovative program, Rise to Action, to educate survivors about the importance of knowing their diagnosis and treatment history and how to access health information and to empower young survivors with advocacy skills.

## *Children's Cause for Cancer Advocacy Continued*

### **Resources Continued**

- The CCCA conducts national advocacy workshops for parents and survivors. Translating Our Voices into Action: Challenges in Pediatric Cancer Advocacy builds on the natural leadership, energy and direct knowledge of its participants.
- The CCCA is active in the Alliance for Childhood Cancer, which represents more than 20 national patient advocacy groups and professional medical and scientific organizations working collaboratively to advance research and policies to prevent cancer and improve public education around the diagnosis, treatment, supportive care and survivorship of children and adolescents with cancer.  
<http://www.allianceforchildhoodcancer.org/acc/Main/>

## CureSearch

[www.curesearch.org](http://www.curesearch.org)

CureSearch represents the combined efforts of the Children's Oncology Group (COG) and the National Childhood Cancer Foundation (NCCF), two organizations united by a common goal: reaching the day when every child with cancer can be guaranteed a cure. As partners in this search, each arm of CureSearch has vital responsibilities covering research, care, advocacy and fund-raising. The funds support the work of CureSearch, the world's largest organization of doctors, nurses and scientists dedicated to scientific discovery and compassionate cures for infants, children, teens and young adults with cancer at more than 200 member institutions throughout North America and abroad.

### Partnering with CureSearch

Use the directory of COG member institutions available at <http://www.curesearch.org> to locate a pediatric cancer treatment facility near you.

### Community Engagement Activities

- Leverage the pediatric oncology expertise of COG members near you for local programming, screening discussion sessions and surrounding media activity.
- Contact COG institutions to connect with patients and families who might be interested in participating in outreach activities.

### Resources

CureSearch.org provides:

- Comprehensive and up-to-date medical information that is customized to a child's diagnosis, age and treatment phase. All content is written in easy-to-understand language and maintained by COG medical experts.
- Psychosocial advice that is written both by health professionals and by parents of children with cancer who understand the journey with the disease. This section includes information about coping strategies as well as practical advice about interacting with the health care team, dealing with insurance issues and maintaining a strong family unit despite the stressors of the treatment process.
- Basic information about the clinical trial process that empowers a family to feel more educated in the world of research. The clinical trial section will soon be enhanced by a clinical trial matching service, allowing users to identify available trials in hospitals nationwide.
- An expansive resource directory that provides information about local and national resources as well as about books and videos relating to the childhood cancer journey.

## ***CureSearch Continued***

### **Resources Continued**

- A discussion board that establishes a community for parents, families, patients, survivors and friends who have been touched by childhood cancer. The discussion board allows visitors to share information and support with others who have similar issues.
- The Support CureSearch section of the website provides a mechanism for families, friends and health professionals to become involved in increasing awareness of childhood cancer. The site also provides information on current initiatives to increase funding to childhood cancer research.

## Gilda's Club Worldwide

[www.gildasclub.org](http://www.gildasclub.org)

Gilda's Club Worldwide is a free cancer support community for men, women and children with any type of cancer and their family and friends. Membership is offered free of charge to people at any stage of their experience with cancer. Through participation in groups, lectures, workshops and social events, members build social and emotional support and learn to live with cancer. There are 20 Gilda's Clubs throughout the United States and Canada.

### Partnering with Gilda's Clubs

- Locate a Gilda's Club chapter near you at <http://www.gildasclub.org/wheretofindus/>.
- Gilda's Club can provide:
  - Links to families and cancer survivors interested in being involved.
  - Support and resources for children and young adults who are cancer survivors or who have a family member or friend with cancer.

### Community Engagement Activities

- Host a screening of A LION IN THE HOUSE module(s) at a Gilda's Club.
- Support SurvivorAlert! event planning and outreach in underserved communities in conjunction with the CDC SurvivorAlert! project.

### Resources

- Noogieland is both the Gilda's Clubs program and a play area for children as well as a supplement to the core program for parents who are members. In a special area of every clubhouse, activities are conducted for children impacted by cancer, whether directly or by having a family member or friend with cancer. Most Gilda's Clubs also have several kinds of activities for teens, who frequently volunteer in many parts of the clubhouse.
- Weekly programming is offered to address the often-neglected social and emotional needs of cancer survivors and their families and friends, in a unique and innovative way through a well-defined program of education and support activities.

## Health Ministries Association (HMA)

[www.HMAAssoc.org](http://www.HMAAssoc.org)

The Health Ministries Association (HMA) is a multifaith membership organization of professional and lay leaders serving within faith communities. The mission of the HMA is to encourage, support and develop whole-person ministries that integrate faith and health. The HMA is dedicated to networking, educating, supporting and sharing a myriad of faith/health ministries. The organization believes in the future of paradigm shifts, creative collaboration and healthier communities through the promotion of whole-person health through faith groups in the communities they serve.

### Partnering with the HMA and Faith Communities

- The HMA has chapters in 27 states that you can locate on their website at: [http://www.HMAAssoc.org/chapter\\_roster.html](http://www.HMAAssoc.org/chapter_roster.html)
- Find the national offices of faith groups or religious denominations that have an active interest in programs related to health ministry at: <http://www.HMAAssoc.org/faithgrouplinks>. At each of these sites, the “Find a Church” search can lead you to local churches and potential connections with those who minister to families facing the illness or the loss of a child.

### Community Engagement Activities

- Facilitate planning and communication between the faith community, oncology teams, cancer support organizations and other members of the LION IN THE HOUSE collaborative.
- Host a screening of A LION IN THE HOUSE module(s) for faith community members, addressing how support can be developed or strengthened for families whose children face life-threatening illness.
- Plan and present a LION IN THE HOUSE workshop for state or regional faith-based conferences explaining the process and value of faith communities partnering with medical and nursing professionals in supporting families through end-of-life and bereavement care.
- Plan and present a LION IN THE HOUSE workshop for medical or nursing conferences explaining the process and value of faith communities partnering with the medical and nursing professions in supporting families through end-of-life and bereavement.

## ***Health Ministries Association Continued***

### **Resources**

The HMA website offers an opportunity for nurses, clergy and chaplains to obtain contact hours of continuing education approved by their professional associations at [http://www.HMAAssoc.org/continuing\\_education.html](http://www.HMAAssoc.org/continuing_education.html). The easy-to-follow directions for completing the module and receiving the certificate are available at the site.

## Hope Street Kids

[www.hopestreetkids.org](http://www.hopestreetkids.org)

Hope Street Kids is a children's initiative of the Cancer Research and Prevention Foundation. The program was founded by Congresswoman Deborah Pryce and Randy Walker, in memory of their nine-year-old daughter, Caroline. The mission of Hope Street Kids is to eliminate childhood cancer through cutting-edge research, advocacy and education. Hope Street Kids is committed to funding both public and private research efforts through fund-raising initiatives and by providing leadership in encouraging new and innovative research investigations.

### Partnering with Hope Street Kids

Hope Street Kids can provide support to local collaboratives in the following ways:

- Provide linkages to medical professionals, researchers, patients and families who might like to be involved or could serve as spokespeople on the issues and focus areas from the various modules in the film.
- Using the power of Congress and the combined influence of a coalition of organizations that share our interests, Hope Street Kids works to: increase federal funding for research, speed delivery of promising new therapies, educate more pediatric cancer professionals, make clinical trials of new treatments available to greater numbers of children, increase access to quality care, and expand support for the emotional and social needs of families and children.
- Encourage and support the development of educational tools for medical professionals related to the needs of childhood cancer patients and their families.

### Community Engagement Activities

- Host a Congressional briefing and/or screening of A LION IN THE HOUSE module(s) for policymakers, community leaders and other change agents who can impact care and resources for families faced with childhood cancer.
- Utilize the LION IN THE HOUSE module on palliative care to help educate pediatric oncology fellows in collaboration with Hope Street Kids' pilot project at Columbus Children's Hospital to develop a training curriculum for pediatric oncology fellows on palliative care and end-of-life issues.

## *Hope Street Kids Continued*

### **Resources**

- An online parent guide with key questions to ask at diagnosis, in seeking treatment and clinical trials and with tips for resources and support is available at [http://www.hopestreetkids.org/parent\\_guide/diagnosis.php](http://www.hopestreetkids.org/parent_guide/diagnosis.php).
- An article about the do's and don'ts of being an effective childhood cancer advocate is available at [http://www.hopestreetkids.org/advocacy\\_education/dos\\_and\\_donts.php](http://www.hopestreetkids.org/advocacy_education/dos_and_donts.php).
- On a case-by-case basis, Hope Street Kids also helps to direct families facing a diagnosis of childhood cancer to the most useful resources or medical expertise in their region.

## Intercultural Cancer Council (ICC)

[iccnetwork.org](http://iccnetwork.org)

The Intercultural Cancer Council (ICC) promotes policies, programs, partnerships and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States and its associated territories. Baylor College of Medicine assumes fiscal and organizational management for the ICC and provides it with a national office and a website. The ICC hosts a biennial symposium that shines a spotlight on the issue of disproportionate cancer incidence, morbidity and mortality in minority and medically underserved populations in the United States and its associated territories.

### Partnering with the ICC

Locate members of the ICC Regional Network Leadership at this location on its website <http://iccnetwork.org/who/regionalnetworkleadership.htm>. They may in turn be able to connect you with local contacts and organizations who can speak on issues of cancer health disparities.

### Community Engagement Activities

- Facilitate community-based screenings of A LION IN THE HOUSE and support discussion on cancer health disparities.
- Utilize A LION IN THE HOUSE module(s) to support professional education in medical and school settings, exploring issues of cultural competence and cancer health disparities.
- Support and host survivor alert events and outreach in underserved communities in conjunction with the CDC SurvivorAlert! project.

### Resources

“Children/Adolescents and Cancer” is an ICC fact sheet that covers research on disparities in child cancer care and outcomes <http://iccnetwork.org/cancerfacts/cfs9.htm>.

## The Lance Armstrong Foundation (LAF)

[www.livestrong.org](http://www.livestrong.org)

The Lance Armstrong Foundation (LAF) inspires and empowers people affected by cancer. The LAF helps people with cancer focus on living and believes that unity is strength, knowledge is power and attitude is everything. From the moment of diagnosis, the LAF provides the practical tools and information that people with cancer need in order to live life on their own terms. The LAF serves its mission through advocacy, public health and research. Founded in 1997 by cancer survivor and champion cyclist Lance Armstrong, the LAF is located in Austin, Texas.

### Partnering with the LAF

The LAF Community Program provides financial support and capacity-building counsel for community-centered initiatives that address the physical, emotional and practical challenges of cancer. Through its Community Program, the LAF awards grants to community nonprofit organizations to serve the needs of people living with cancer as identified by the National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. To learn more about the LAF's current Community Program partners as well as future funding opportunities, please visit <http://www.livestrong.org/communityprogram>.

### Community Engagement Activities

- Collaborate with the LAF's Community Program partners to host a screening of A LION IN THE HOUSE at community events, conferences and trainings organized by local cancer organizations.
- Explore ways to utilize the film and LAF resources to increase access to survivorship support programs. At the same time, explore ways to work together with the LAF advocacy team to raise awareness of survivorship issues.

### Resources

The LAF offers support and assistance to help people face the everyday physical, emotional and practical challenges of cancer. Cancer survivors may access the LAF's tools and resources in three ways:

1. Visit <http://www.livestrong.org> for all of the LAF's survivorship resources online.

## *The Lance Armstrong Foundation Continued*

### Resources Continued

2. The **LIVESTRONG™** Survivorship Notebook helps cancer survivors organize and guide their cancer experience. The portable three-ring binder features stories of cancer survivors and includes sections to organize important information and to add personal records. To order a **LIVESTRONG™** Survivorship Notebook, visit <http://www.livestrong.org/notebook>. The notebook is free, you pay only for shipping and handling charges, which average less than \$10 in the United States.
3. **LIVESTRONG™** SurvivorCare is designed to help survivors face the everyday challenges of cancer through education, qualified referrals and counseling services from professional oncology social workers. **LIVESTRONG™** SurvivorCare provides:
  - Individual counseling
  - Assistance with legal, financial and/or insurance issues
  - Matching to clinical trialsTo access the services available through **LIVESTRONG™** SurvivorCare, call toll free 866-235-7205 or visit <http://www.livestrong.org/survivorcare>.

## The Leukemia & Lymphoma Society (LLS)

[www.lls.org](http://www.lls.org)

The Leukemia and Lymphoma Society (LLS), headquartered in White Plains, N.Y., with 66 chapters in the United States and Canada, is the world's largest voluntary health organization dedicated to funding blood cancer research and providing education and patient services. The LLS's mission is to cure leukemia, lymphoma, Hodgkin's disease and myeloma and improve the quality of life of patients and their families.

### Partnering with the LLS

Locate chapters near you on the LLS website. Chapter staff and volunteers can provide support to local collaboratives in the following ways:

- Provide expertise and serve as spokespeople on patient issues and focus areas.
- Provide linkages to patients and families who might like to be involved.
- Be a key resource of support to families facing childhood cancer.

**Note:** All of the children in A LION IN THE HOUSE have a form of leukemia or lymphoma.

### Community Engagement Activities

- Feature A LION IN THE HOUSE module(s) at LLS conferences and training workshops and community events to focus discussion on cancer health disparities and survivorship.
- Support survivor event planning and outreach in conjunction with the CDC SurvivorAlert! project.
- Utilize the module(s) as a teaching tool in conjunction with the Trish Green Back to School Program for Children with Cancer.

### Resources

- The LLS Information Resource Center (IRC), a call center staffed by master's level social workers, nurses and health educators who provide information, support and resources to patients and their families and caregivers. IRC information specialists are available at 800-955-4572, Monday through Friday, 9 a.m. to 6 p.m. ET.
- Pediatric Cancer Educational Series, free teleconferences with childhood cancer experts. Upcoming topics include school accommodations children need and should be provided with when they return to school (February); and parenting a child with cancer (May). Call the IRC at 800-955-4572 for details.

## *The Leukemia & Lymphoma Society Continued*

### **Resources Continued**

- The Trish Greene Back to School Program for Children with Cancer is designed to increase communication among health care professionals, parents, patients and school officials to assure a smooth transition from active treatment back to school and daily life.
- New education program offered through the LLS's chapters for K–12 teachers, guidance counselors, school nurses and other school personnel. "Welcome Back: Facilitating the Return to School for Children with Cancer," taught by local medical experts and educators, is designed to teach school personnel about the cognitive effects of cancer treatment, ways to help children overcome educational and social obstacles when returning to school, and how to design specialized education plans.
- Extensive resource information online and in print materials in Spanish and English.
- New free booklet, "Learning & Living with Cancer: Advocating for Your Child's Educational Needs," available by calling the IRC at 800-955-4572.
- Online discussion boards for patients and caregivers.
- Supplementary financial assistance to patients in significant financial need. Learn how to apply at <http://www.lls.org>.

## National Association of Social Workers (NASW)

[www.socialworkers.org](http://www.socialworkers.org)

[www.helpstartshere.org](http://www.helpstartshere.org)

The National Association of Social Workers (NASW) is the largest membership organization of professional social workers in the world, with 153,000 members. Its mission is to promote, develop and protect the practice of social work while enhancing the well-being of individuals, families and communities through its policy work and advocacy. The NASW has chapters in all 50 states, Guam, Puerto Rico and the Virgin Islands and an international chapter. NASW chapters provide a variety of professional products and services, including continuing education programs, annual conferences, newsletters, websites and other forums for exchange of information.

### Partnering with the NASW and Local Social Workers

- Locate your state NASW chapter at <http://www.socialworkers.org/chapters/default.asp> or search for social workers by ZIP code and specialty at <http://www.helpstartshere.org> and click on “Find a Social Worker” at the top of the page.
- NASW members can provide support to local collaboratives in the following ways:
  - Provide expertise and serve as professional speakers on the psychosocial needs of childhood cancer patients and families and available local resources.
  - Provide linkages to individuals, their families and other groups who might like to be involved.

### Community Engagement Activities

- Utilize A LION IN THE HOUSE module(s) and film as a teaching tool with school professionals and related groups.
- Feature A LION IN THE HOUSE module(s) and discussion guide at conferences and trainings for social workers, cancer support organizations and other providers of care for child cancer patients and families.
- Host a screening of A LION IN THE HOUSE module(s) for community leaders addressing how support can be strengthened for families whose children face life-threatening illness.
- Support survivor event planning and outreach in conjunction with the CDC SurvivorAlert! project.
- Utilize A LION IN THE HOUSE module(s) as a teaching tool focusing on addressing cancer health disparities.
- The Help Starts Here website developed by the NASW has a search feature to help individuals and families find a social worker by ZIP code and specialty. There are also specific tools and resources for those coping with cancer at [http://www.helpstartshere.org/health\\_and\\_wellness/cancer/default\\_page.html](http://www.helpstartshere.org/health_and_wellness/cancer/default_page.html).

## ***National Association of Social Workers Continued***

### **Resources**

- The NASW and CancerCare have teamed up to create an online course about the role of social workers in practicing with people affected by cancer called “Understanding Cancer: The Social Worker’s Role.” Visit the NASW website at <http://www.naswwebed.org/> for more information.
- The NASW and the Children's Cause for Cancer Advocacy have partnered to develop a Web-based educational tool for social workers to learn about childhood cancer survivorship and strategies for working with survivors. Information on this tool is available on the NASW website <http://www.socialworkers.org>.

## The National Cancer Institute (NCI)

[www.cancer.gov](http://www.cancer.gov)

The National Cancer Institute (NCI) is a component of the National Institutes of Health (NIH). The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination and other programs related to the cause, diagnosis, prevention and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. The NCI's Cancer Information Service (CIS), the Center to Reduce Cancer Health Disparities and the Office of Survivorship are helping to advise the LION IN THE HOUSE outreach campaign.

### Partnering with State Cancer Control Programs

Locate a Cancer Information Service Regional Office near you at <http://cis.nci.nih.gov/community/Regions/regions.html>.

### Community Engagement Activities

- Host a screening of A LION IN THE HOUSE at CIS regional conferences and trainings.
- Utilize the CIS Regional Partnership Program to network with organizations concerned with reducing cancer health disparities.

### Resources

- Call the NCI CIS at 800- 4-CANCER (422-6237). CIS Information Specialists answer calls in English or Spanish. Another service is LiveHelp, the NCI's live online assistance: <https://cissecure.nci.nih.gov/livehelp/welcome.asp>.
  - The CIS Partnership Program works with nonprofit, private and other government organizations to deliver messages and materials about cancer to people who may have difficulty obtaining health information because of educational, financial, cultural or language barriers.
  - Search for childhood cancer information and learn about clinical trials at <http://www.cancer.gov/cancertopics/types/childhoodcancers>.
  - Find childhood cancer treatment summaries at <http://www.cancer.gov/cancertopics/types/childhoodcancers>.
  - This issue of BenchMarks has an article on pediatric brain tumors and an article on children and cancer immunotherapy: <http://www.cancer.gov/newscenter/benchmarks-vol5-issue2>.
  - "NCI Health Information Tip Sheet for Writers: Childhood Cancers" <http://www.cancer.gov/newscenter/tip-sheet-childhood-cancers>.

## *The National Cancer Institute Continued*

### Resources Continued

- NCI research on childhood cancers
  - “Young People with Cancer: A Handbook for Parents”  
<http://www.cancer.gov/cancertopics/youngpeople>
  - “Care for Children and Adolescents with Cancer: Questions and Answers”  
<http://www.cancer.gov/cancertopics/factsheet/NCI/children-adolescents>
  - Childhood cancer resources: <http://ctep.cancer.gov/resources/child.html>
  - Pediatric oncology branch of the NCI:  
<http://home.ccr.cancer.gov/oncology/pediatric/>
  - Office of Cancer Survivorship: <http://survivorship.cancer.gov>
  - Center to Reduce Cancer Health Disparities: <http://crchd.nci.nih.gov/>
  - Institute of Medicine reports on childhood cancer: <http://iom.edu>

## National Hospice and Palliative Care Organization (NHPCO)

[www.nhpc.org](http://www.nhpc.org)

The National Hospice and Palliative Care Organization (NHPCO) is committed to improving end-of-life care and expanding access to hospice and palliative care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones. The NHPCO is a nonprofit organization representing 3,000 hospice and palliative care programs and more than 10,000 professionals in the United States. Priority areas include advocating for the seriously ill and their families, developing public and professional education programs, conducting research, and working closely with other organizations that share an interest in end-of-life care.

### Partnering with Hospice, Palliative Care and Bereavement Programs

- Search for a hospice, palliative care or bereavement program in your area at: <http://www.nhpc.org/custom/directory/main.cfm>. Additionally, you can search for end-of-life coalitions in your viewing area using this same online search tool.
- Local end-of-life coalitions and programs can assist you in identifying expert spokespeople in pediatric palliative care and possibly connect you to family members who would like to be advocates on these issues.

### Community Engagement Activities

- Host a community screening of A LION IN THE HOUSE using the “End of Life” clip, available on DVD, to explore ways your community might better support families faced with losing a child. Explore settings such as the faith community and schools.
- Utilize the LION IN THE HOUSE DVD at conferences and training for professionals in health care, school professionals, those in faith ministries and youth development programs.
- Facilitate group viewings of the LION IN THE HOUSE series as it airs, providing an opportunity to convene and discuss all of the end-of-life content in the film.
- Explore ways to utilize the film and NHPCO resources to support various state and community initiatives to improve pediatric palliative care.

### Resources

- Families can search for a provider in their community at <http://www.nhpc.org/custom/directory/main.cfm> in Spanish and English. The NHPCO directory offers a search for hospice, pediatric palliative care, community bereavement care, grief counseling and more.

## ***National Hospice and Palliative Care Organization Continued***

### **Resources Continued**

- Caring Connections is an initiative of the NHPCO that offers a wide range of free materials about end-of-life care. Resource information is available at <http://www.caringinfo.org> and through the Caring Connections HelpLine at 800-658-8898.
- The NHPCO has developed resources for health professionals on pediatric palliative care under the auspices of the Children's Project on Palliative/Hospice Services. These materials are available through the NHPCO Marketplace at <http://www.nhpc.org/marketplace>:
  - *Caring for Kids: How to Develop a Home-Based Support Program for Children and Adolescents with Life-Threatening Conditions* (CD only)
  - *Education and Training Curriculum for Pediatric Palliative Care*
  - *Compendium of Pediatric Palliative Care*
- <http://www.PartnershipForParents.org> is a national website for parents of seriously ill children sponsored by the Children's Hospice and Palliative Care Coalition. The website offers practical information, resources and support for parents whose children are receiving curative treatment, palliative or end-of-life care. The site also includes information for families grieving the loss of a child.

## Oncology Nursing Society (ONS)

[www.ons.org](http://www.ons.org)

The Oncology Nursing Society (ONS), the largest professional oncology association in the world, is composed of more than 32,000 registered nurses and other health care providers dedicated to excellence in oncology nursing (patient care, education, research and administration) and quality cancer care for patients and their families across the wellness/illness continuum. ONS represents a diverse group of professionals with more than 218 chapters in all 50 states.

### Partnering with the ONS

Locate chapters near you at <http://www.ons.org/membership/chapters.shtml>. Chapter members can provide support to local collaborative efforts in the following ways:

- Provide expertise and serve as spokespersons on medical issues and focus areas.
- Provide linkages to patients and families and other interested parties who might wish to be involved.
- Identify strategies that may be useful in promoting A LION IN THE HOUSE.

### Community Engagement Activities

- Feature A LION IN THE HOUSE module(s) and discussion guides at conferences and trainings for oncology teams, cancer support organizations and other providers of care for pediatric cancer patients and families.
- Host a screening of A LION IN THE HOUSE module(s) for community leaders addressing how support can be strengthened for families whose children face life-threatening illness.
- Support survivor event planning and outreach in conjunction with the CDC SurvivorAlert! project.
- Utilize A LION IN THE HOUSE module(s) as a teaching tool focusing on improved palliative, end-of-life and bereavement care.

### Resources

- <http://CancerSymptoms.org> is an ONS website designed for patients and caregivers to provide information on learning about and managing common symptoms secondary to cancer and its therapies.
- The Association of Pediatric Oncology Nurses also publishes selected patient/family resource materials. For more information, visit the APON website at <http://www.apon.org>.

## **PADRES Contra El Cáncer**

[www.IamHope.org](http://www.IamHope.org) / [www.YoSoyEsperanza.org](http://www.YoSoyEsperanza.org)

PADRES Contra El Cáncer is an organization committed to improving the quality of life for Latino children with cancer and their families. Founded in 1985, PADRES has assisted more than 4,200 families and more than 16,000 extended family members residing in southern California with support services that include: case management; crisis intervention; patient/family navigation; childhood cancer education and family health and well-being education seminars; community referrals; daily living assistance with food and transportation; and ongoing quality-of-life events. PADRES programs are designed to be culturally relevant, family-centered and community-based. All PADRES programs, activities and services, although primarily oriented to the Latino community, serve childhood cancer patients from all races and ethnic origins. No family is ever turned away.

### **Partnering with PADRES**

PADRES services are focused in the Los Angeles area; however, they do offer support and referrals by phone to families seeking assistance in larger metropolitan cities in the United States and parts of Mexico and Central America.

### **Community Engagement Activities**

In the Los Angeles area, host a screening of A LION IN THE HOUSE module(s) for policymakers, community leaders and other change agents who can impact care and resources for families faced with childhood cancer.

### **Resources**

The PADRES website has a list of national links to resource organizations and cancer centers for childhood cancer patients and their families:

<http://www.iamhope.org/resourcelinks.html>