

A Lion in the House

a film by Steven Bognar and Julia Reichert

COMMUNITY ENGAGEMENT CAMPAIGN



COMMUNITY ENGAGEMENT CAMPAIGN REPORT: EXECUTIVE SUMMARY

The **A LION IN THE HOUSE** Community Engagement Campaign spearheaded by ITVS built an impressive coalition of partners—including some of the nation’s leading public health organizations, created a remarkable array of resources, and produced a nationwide series of events and projects that achieved widespread visibility and impact for the campaign.

From the U.S. Capitol to the CDC in Atlanta, from Native American reservations in New Mexico to Latino communities in Southern California, and from nationally syndicated radio programming on NPR to the historic primetime common carriage broadcast on PBS, **A LION IN THE HOUSE** touched millions of people across the country, including tens of thousands of health care and social service professionals whose ongoing work carries forward the campaign’s objectives.

CAMPAIGN GOALS:

- Engage and strengthen local collaborations among caregivers, educators, medical professionals and others, including families and young people living with cancer.
- Support patients and their families, professionals and the general public, with educational resources and opportunities for community engagement in pediatric cancer issues
- Empower young adult cancer survivors to take proactive steps to ensure their long-term health and help them and their families become skilled advocates for change.
- Educate communities about the need for palliative, hospice and bereavement care for children and families and stimulate efforts to improve these services.
- Increase public awareness of disparities in diagnosis, treatment and survivorship among underserved population and help create momentum for change regarding gaps in care and barriers to care.
- Promote efforts by healthcare and social service professionals to provide culturally sensitive and appropriate support.

NATIONAL PARTNER ORGANIZATIONS:

American Academy of Pediatrics • American Cancer Society • Association of Oncology Social Work • Children’s Cause for Cancer Advocacy • CureSearch National Childhood Cancer Foundation • CureSearch Children’s Oncology Group • Gilda’s Club Worldwide • Health Ministries Association • Hope Street Kids • Intercultural Cancer Council • The Lance Armstrong Foundation • The Leukemia & Lymphoma Society • National Association of Social Workers • National Black Nurses Association, Inc. • National Hospice and Palliative Care Organization • Oncology Nursing Society and Association for Pediatric Oncology Nurses • Padres Contra El Cancer

National Campaign Advisors: Center for Disease Control and Prevention • National Cancer Institute

A LION IN THE HOUSE HIGHLIGHTS:

- Extensive national use of more than 1000 ‘Focus Area’ DVD modules a year prior to broadcast, supported by partner developed campaign materials (86,000 downloads) inspired local planning and provided a sustainable resource for professional and community education.
- A unique partnership between ITVS and the Lance Armstrong Foundation provided \$100,000 for station outreach activities in 10 markets and supported an intensive two-day training at CPB bringing together stations and their local partners with national leaders and researchers, developing longer-term capacity in the PTV system for outreach work on community public health and cancer health issues.
- The ITVS Campaign funded and inspired dozens of hours of locally developed programming on public television and radio addressing childhood cancer needs through a local lens. WHYY’s nationally distributed radio program reached tens of thousands of people in various markets.
- The A LION IN THE HOUSE Campaign included more than 150 special events produced by ITVS, PTV station partners, National Partner organizations, and other local and regional partners which helped the Campaign reach over 40,000 thousand people directly, including families, cancer survivors, health care and social service professionals, and other community members around the country.
- 800 nurses and social workers watched the broadcast and received Continuing Education Credits through an initiative of the Health Ministries Association, promoted by National Partners.
- WGBH Boston partnered with their state Cancer Control Program to develop and promote an on-line Cancer Survivor Survey utilized in 5 New England states.
- Pediatric and Adolescent Cancer Coalitions were formed in Chicago, IL and SE Texas as a result of the LIONS campaign. The Texas Cancer Council and Medical Association held their first state-wide conference on pediatric cancer.
- ITVS and several National Partners including the CDC produced a Congressional screening and briefing event in the U.S. Capitol Building for members of Congress, Congressional staff, and other policy professionals; more than 100 turned out for the event, including Congresswoman Deborah Pryce, who later spoke about the broadcast at a news conference on the Capitol steps, and from the House floor. She also authored a “Dear Colleague” letter to all members of the House and Senate urging them to tune-in.
- At least ten public television stations hosted call-in lines staffed by experts in pediatric cancer and palliative care supporting and connecting families with resources and connecting organizations with motivated volunteers.
- The A LION IN THE HOUSE Campaign succeeded in reaching minority and disadvantaged communities around the country. Padres Contra El Cancer convened more than 200 community members for a screening and discussion on cancer health disparities in the Latino community in Los Angeles in June 2006, and KNMW led a state-wide project in New Mexico focusing on the state’s Spanish-speaking and Native American communities. Other projects focused on inner-city and African American Communities.

CAMPAIGN RESOURCES DISTRIBUTED TO DATE:

• Discussion Guides Downloaded from itvs.org:	55,300
• Campaign Toolkits and other resources downloaded:	30,822
• Education and Outreach Module DVDs distributed:	1,200
• Campaign Postcards distributed	125,000
• Campaign Website page views	122,645

MAJOR NATIONAL CONFERENCES FEATURING A LION IN THE HOUSE:

The campaign reached directly more than 30,000 health care professionals, social service professionals, and cancer and healthcare advocates through presentations, workshops, and other activities at more than 30 national and regional professional conferences. Highlights include:

• C-Change, Washington, DC, October 2005 and May 2006	800 participants
• Association of Pediatric Oncology Nurses, October 2005	1200 participants
• National Cancer Institute (NIH), October 2004	150 participants
• National Hospice and Palliative Care Organization, November 2004 and April 2006	3000 participants
• Oncology Nursing Society , April 2005 and May 2006	13000 participants
• Intercultural Cancer Council, March 2004 and April 2006	2500 participants
• Association of Oncology Social Work, April 2006	500 partocipants
• Lance Armstrong Foundation “Ride for Roses,” October 2003	1000 participants
• Centers for Disease Control, Annual Cancer Control Meeting, November 2004	260 participants

ITVS/LANCE ARMSTRONG FOUNDATION STATION OUTREACH GRANTS TO:

WGCU Fort Meyers, FL • WPBA Atlanta, GA • UNC-TV, North Carolina State-wide • MPT Maryland State-wide • WHYY Philadelphia, PA • WCET, Cincinnati, OH • WLJT Martin, TN • TPT/KTCA St. Paul, MN • KNME Albuquerque, NM • KTOO - Juneau, AK

A LION IN THE HOUSE EVENTS:

The A LION IN THE HOUSE Campaign included more than 150 special events produced by ITVS, PTV station partners, National Partner organizations, and other local and regional partners which helped the Campaign reach over 40,000 people directly, including families, cancer survivors, health care and social service professionals, and other community members around the country. Highlights include:

- ITVS, CPB, CDC, and others produced a Congressional screening and briefing event in the U.S. Capitol Building for members of Congress, Congressional staff, and other policy professionals. More than 100 turned out for the event.
- Padres Contra El Cancer convened more than 200 community members for a screening and discussion on cancer health disparities in the Latino community in Los Angeles in June 2006.
- WGBH Boston produced a series of screenings and discussions in public libraries and other venues in Massachusetts and four other New England states.
- More than 20 ITVS Community Cinema screening events in markets from coast to coast brought communities together with leading health care and social service providers and cancer health advocates for discussion, debate and community learning.
- CET in Cincinnati, OH produced a Health Fair at the downtown public library that brought scores of people together with leading health care providers and public health educators to raise awareness of cancer warning signs, treatment options, and prevention strategies. More than 80% of attendants reported learning a great deal from the event.
- Maryland Public Television convened a screening and discussion with Johns Hopkins University and the Maryland Film Festival that included filmmakers Julia Reichert and Steven Bognar, along with documentary subject Dr. Arceci.

A LION IN THE HOUSE IMPACT:

Integrated care communities; facing palliative care; focus on childhood cancer & survivorship issues; raising awareness around cancer health disparities; and professional education

INTEGRATED CARE COMMUNITIES—A HOLISTIC APPROACH TO CANCER CARE:

Recognizing the unique burdens that pediatric cancer places on families, the campaign succeeded in stimulating efforts to provide more and better resources to families, and brought together different facets of pediatric cancer care in order to promote a more holistic, integrated care experience for children and their families. Highlights include:

- KLRU in Austin, TX partnered with the University of Texas Medical Center to establish the Adolescent Cancer Coalition which continues to bring together numerous local organizations working to meet the many medical, social, economic, and psychological support needs of families confronting childhood cancer. This is central Texas' first interdisciplinary pediatric cancer care coalition.
- In Chicago, IL, Gilda's Clubs joined Northwestern University Cancer Center, Children's Memorial Hospital and others to co-host a dozen events to educate the community about the many resources available for families battling cancer. The partners continue to collaborate toward identifying more and better ways to provide integrated cancer support across medical, social, and personal areas.
- South Carolina Cancer Control Program brought together churches, hospices, hospitals and other health and human service organizations to produce more than a dozen LIONS events, and created a local coalition to promote integrated care and community-wide support for families affected by cancer.
- WPBA Atlanta engaged the Atlanta Public Schools in a partnership to raise awareness among school nurses and health-related community service organizations about the special needs of children fighting cancer, and provided training on referrals to a variety of organizations that can provide support to families.
- Through presentations at the National Cancer Institute, the Centers for Disease Control, C-Change, and other leading cancer conferences and meetings, the LIONS campaign reached directly thousands of health and social service professionals with its core message that cancer care must transcend the medical, to include social service, economic, psychological, and logistical support.

PUTTING PEDIATRIC CANCER BACK ON THE AGENDA:

About 12,500 children and youth are diagnosed with cancer in the U.S. each year—a small number compared to adult cancers. This smaller population, coupled with the remarkable progress in treating many types of pediatric cancer, has made childhood cancer a lower priority area for many cancer and public health advocacy organizations. The LIONS Campaign succeeded in stimulating dialogue, planning, and resource development among policymakers and advocates focused specifically on pediatric cancer.

- The Centers for Disease Control and Prevention’s Comprehensive Cancer Control Program coordinates 50 state-level Cancer Control organizations, each of which maintains a State Cancer Plan. As a result of CDC’s central role in the campaign, pediatric cancer is a much higher visibility topic among CDC-funded state-level Cancer Control organizations.
- ITVS produced a briefing and discussion event in the U.S. Capitol Building for members of Congress and their staffs to provide updates and information about the latest in pediatric cancer issues. The CDC, Oncology Nursing Society, Leukemia & Lymphoma Society and other experts made presentations.
- Representative Deborah Pryce of Ohio, Co-Chair of the House Cancer Caucus, worked with ITVS to feature A LION IN THE HOUSE at a press conference on the steps of the U.S. Capitol during child cancer awareness week (Gold Ribbon Days). Rep. Pryce also authored a “Dear Colleague” letter to all 535 members of the House and Senate urging them to watch the LIONS broadcast and consider further support for childhood cancer and spoke about the broadcast from the floor of the House.
- C-Change is the largest coalition of public health and healthcare advocacy organizations in the country focused on battling cancer, supporting survivors, and working to improve the cancer health care system. ITVS led significant presentations about the LIONS film and campaign at two consecutive biennial meetings of C-Change, placing pediatric cancer high on the agenda of the nation’s leading cancer health groups.

BREAKING THE SILENCE—FACING PEDIATRIC PALLIATIVE AND END-OF-LIFE CARE:

Among the most difficult areas in pediatric cancer care are the choices associated with palliative and/or end-of-life care. While there is a growing effort in the U.S. to improve pediatric palliative care, there remains a shortage of resources and experience in caring for children at end-of-life in both hospitals and hospice settings. The LIONS Campaign made significant contributions to these efforts.

- Through its involvement with the campaign, the National Hospice and Palliative Care Organization undertook to evaluate and identify pediatric-specific hospice and palliative care resources and make them easily available through a dedicated on-line database. This information had never before been aggregated specifically for pediatric services, making resources far more accessible to families in their time of need.
- Significant pediatric end-of-life content in the LIONS series sparked a national dialogue on one of the least visible issues in pediatric cancer, leading many surviving parents, siblings, and others to seek support for themselves and to advocate for the need for greater focus on palliative and end-of-life issues.
- Too often, palliative care is delayed or underutilized in pediatric cases because many parents and some health care professionals mistakenly associate it with late-stage or end-of-life care. This confusion can lead to unnecessary suffering and suboptimal pain management for many pediatric cancer patients. The campaign highlighted this issue in many professional and clinical settings, and made a significant contribution to the promotion of early-stage palliative care for childhood cancer.
- The Center for Practical Bioethics in Kansas City, MO produced a youth leadership forum on pediatric end-of-life issues for students considering careers in health care. This discussion, emphasizing communication among loved-ones, balancing hope and expectations, and the needs of terminal patients exemplifies the larger national dialogue on palliative and end-of-life issues sparked by the LIONS campaign.
- NHPCO distributed DVD modules, Discussion Guides, and End-of-Life Fact Sheets to more than 50 leading hospice and palliative care advocacy organizations as a key resource in professional education, and included articles in four separate editions of its electronic newsletter which is distributed to nearly every hospice and palliative care organization in the country (more than 20,000).

CHILDHOOD CANCER SURVIVORSHIP—EDUCATING FAMILIES & POLICYMAKERS:

Recent studies have shown that childhood cancer survivors continue to face significant health and other consequences of their illness long after the cancer has disappeared. Continuing support for pediatric cancer survivors is crucial for long term health, and the LIONS campaign joined with leading national partners to promote the need for better follow-up care, and to educate survivors and families on their own long-term needs.

- The Centers for Disease Control provided direct support to the LIONS campaign through a grant to the filmmakers to support the SurvivorAlert! project. This project funded dozens of events around the country for young cancer survivors focused on improving follow-up screening among these young adults, alerting them to long-term effects, and empowering them to seek the support they need to thrive.
- TPT, with its local partners, produced and broadcast *A LION IN THE HOUSE- Minnesota Connects*, a half hour community forum with an expert panel exploring issues of survivorship and community support. The program emphasized the importance of survivor follow-up and encouraged young people to become leaders and supporters of youth who are just beginning their cancer journey.
- WHYY produced a radio documentary, *Childhood Lost and Found*, focusing on cancer survivorship which was offered nationally through NPR feed. The hour-long program featured local and national experts, interviews with families and survivors and the LIONS producers. Twelve public radio stations reported airing the documentary in conjunction with the LIONS television broadcast, and it continues to be available for rebroadcast.
- Among the campaign's key goals in public education was to build capacity among child cancer survivors to tell their own stories as a way of helping communities to understand the real impact of the pediatric cancer experience. More than 20 local TV and radio broadcasts featured a diverse group of young cancer survivors who offered personal reflections on their experiences and the realities of fighting and surviving cancer.
- KTOO in Juneau, Alaska tackled the challenges of cancer survivorship in Alaska's more isolated communities. Survivor follow-up care is sparse in the largest U.S. state, with most treatment and screening opportunities no closer than Seattle, WA. KTOO's grant-funded project worked to identify and build connections among Alaska's survivorship resources in Anchorage and Juneau, and their promotional efforts led to a significant donation to support children with cancer in Juneau.

CANCER HEALTH DISPARITIES—RAISING AWARENESS ABOUT ACCESS AND TREATMENT:

Recognizing that disparities exist in access to health care for different communities, the LIONS campaign worked to increase awareness of disparities in diagnosis, treatment, and survivorship, and helped to create momentum for change.

- The Intercultural Cancer Council—the nation's leading organization focusing on cancer health disparities, featured LIONS at two consecutive annual conferences, the nation's largest gathering on the issue of disparities in cancer care.
- The National Cancer Institute's Center to Reduce Cancer Health Disparities produced a screening and discussion event at the National Institutes of Health, recognizing LIONS as a significant opportunity to educate both professionals and the public about the need for change.
- Los Angeles-based Padres Contra el Cancer, focused on providing cancer support to the Latino community, was a leader in the LIONS campaign, including providing clinical training on disparities issues to stations and other partners at the LIONS National Training and Workshop.
- KNME Albuquerque's grant funded project succeeded in building a state-wide coalition to bring cancer education and information about care and resources to New Mexico's Native American and Latino populations, whose access to healthcare is less frequent and hampered by language and other cultural barriers.
- CET in Cincinnati focused their LIONS outreach on underserved population in inner-cities in Ohio, creating a partnership with Cincinnati's Public Health Department that led to a school district-wide training of school nurses and a health fair at the downtown public library to educate the community about access to services and resources.

PROFESSIONAL EDUCATION: DEEPENING DIALOGUE AND BUILDING CAPACITY:

Among the campaign's central tactics and most important outcomes are its contributions to professional education. Through appearances at more than 30 professional conferences and collaborations with leading professional societies and associations, LIONS engaged tens of thousands of health care and social service professionals on issues related to the campaign's core goals. In addition, the LIONS campaign provided a significant level of training and resources to public television outreach and communications professionals aimed at building longer-term capacity to engage on cancer and healthcare issues.

- Health Ministries Association developed an on-line curriculum to accompany the LIONS broadcast that would provide nurses and social workers with Continuing Education Units required in their fields. More than 700 nurses and social workers applied for and received credit for their work in the LIONS curriculum.
- The Association of Pediatric Oncology Nurses featured LIONS at its annual conference in 2005, and worked with ITVS to distribute the LIONS Module DVD to all of its 44 local chapters, 23 of which used the materials to hold professional development seminars at hospitals, hospices, or other clinical settings.
- The ITVS LIONS Campaign team convened a two-day training and workshop in Washington DC attended by 10 PTV stations, their local partner organizations, 13 National Partners, and representatives from CPB, PBS and others to provide education and training on core clinical issues in pediatric cancer. ITVS-granted stations participated in a rigorous two-day curriculum delivered by some of the foremost authorities on cancer health care in the country.

Widespread use of A LION IN THE HOUSE materials and strong participation in events nationwide evidence a major contribution to the national discussion on pediatric cancer

- Nearly 100,000 Discussion Guides, Fact Sheets, Toolkits, Postcards and DVD Modules (combined total) were distributed to PTV stations and national and local partners for events, trainings, and other projects, helping to frame the national discussion and contextualize the national broadcast of A LION IN THE HOUSE.
- More than 100,000 unique hits to the A LION IN THE HOUSE Campaign Website evidence the public response to campaign materials and events.
- With over 40,000 people attending LIONS events and over 30,000 health care and social service professionals reached through conference activity, the Campaign engaged local and professional communities directly on the core goal's and relevant major issues.

Grants to 10 public television stations around the country supported diverse locally-based A LION IN THE HOUSE projects meeting campaign goals in several areas, including:

- **CET—Cincinnati:** CET and their partners geared their activities to reach underserved audiences and to train others to reach and serve this audience. The partnership with the city public health department resulted in a school district-wide training of school nurses, and a health fair at the downtown public library resulted in more than 80% of the surveyed participants reporting they gained knowledge about resources and services for their children and 40% reporting confidence they would utilize these resources.
- **KNME—Albuquerque:** KNME's A LION IN THE HOUSE project was also called Un León en Casa y en el Pueblo y en el Hogan, as New Mexico has many different kinds of houses and communities – the Spanish Casa, The American Indian Pueblo and the Navajo Hogan, to name a few. An extensive partner group (20 members) reached out to underserved Spanish and Native American speaking communities in New Mexico, focusing on health disparities due to language, differences in cultural context, and poverty. KNME and its 20 partners used multilingual approaches to raise awareness and promote the use of resources available to underserved New Mexico children with cancer. Estimated reach was 620,000.
- **KTOO—Juneau:** KTOO and its partners focused on survivorship. Patients and families in Alaska who receive a diagnosis of childhood cancer must travel great distances for treatment – usually to Seattle, WA. As a result, families face long separations and absences from school and friends. One of the most significant impacts of the LIONS project was to connect the cancer community in Juneau to information and resources in Anchorage and elsewhere. It led to the initiation of a survivor report similar to the Survivor Alert Project, and increased awareness and state support for a Bone Marrow Drive program – particularly in the Native Alaskan community. KTOO used its FM radio station and television station to support two weeks of media focus on the local needs and resources for childhood cancer.

- WHY—Philadelphia: WHY produced a nationally distributed radio documentary, *Childhood Lost and Found*, focusing on cancer survivorship. The hour-long program featured local and national experts, interviews with families and survivors and the LIONS producers. Twelve public radio stations reported airing the documentary in conjunction with the LIONS television broadcast, and it continues to be available for rebroadcast to NPR stations nationwide.
- WPBA—Atlanta: The Atlanta Public Schools partnership and collaboration with the screening preview and outreach efforts has resulted in a heightened awareness among support personnel for the need for appropriate holistic family support including, but not limited to, referrals to community health providers and support groups, homebound instruction, implementation of federally-mandated 504 accommodations, and the establishment of a safe and supportive school environment.”

THE A LION IN THE HOUSE CAMPAIGN CONTINUES:

With the more than 2.5 year central campaign at an end, impact continues through the many partnerships, programs, materials created during the campaign. Additionally, generous support from the Corporation for Public Broadcasting and the Centers for Disease Control and Prevention continues to provide resources and create impact in two key areas:

MyLion.org and the LIONS Youth Community Service Kit

Funded with a \$153,000 outreach grant from the Corporation for Public Broadcasting, the LION IN THE HOUSE Youth Community Service Kit is as an opportunity for youth to earn community service credit around issues of childhood cancer. Correlated with national academic standards, complete service-learning units can be accessed off of the DVD and from the project site, mylion.org. Content is supported with streaming clips from A LION IN THE HOUSE. Through this project, teens can learn empathy, overcome fears, and feel the power and rewards of reaching out to another in need.

Youth participating in service projects are encouraged to join the online community to blog about their experiences and post examples of their projects on the scrapbook page. Teens can earn community service credit in a number of creative ways. Campaign National Partner Youth Service America will offer limited mini-grants, but many of these projects can be done without additional funding.

LIONS Educational DVD Modules

Funded through the Centers for Disease Control & Prevention, a series of 10 targeted DVD modules are being created around specific pediatric oncology subjects. This expanded series will include revised versions of the three outreach modules widely distributed by ITVS. Drawing from the 525 hours of LION content, the modules expand upon the issues raised in the award-winning documentary. Specific themes include: “Nurse-Patient Boundary Issues,” “Impact on Siblings,” “Caregivers and Spirituality” and “Teens with Cancer in Secondary Schools.” The modules will be distributed to medical schools, nursing schools, social work programs and other professional training and re-certification programs.

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