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## **Leukemia and Lymphoma Society**

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There are three major types of blood cancer that can attack a victim at any age: Leukemia, Lymphoma, and Myeloma. Leukemia is a type of cancer that is found in blood and bone marrow and is caused by a rapid production of abnormal white blood cells.<sup>1</sup> There are four broad classifications of leukemia: acute lymphocytic leukemia, acute myelogenous leukemia, chronic lymphocytic leukemia, and chronic myelogenous leukemia.<sup>2</sup> Lymphoma is a growth of abnormal lymphocytes in the lymphatic system and is divided into two major categories: Hodgkin lymphoma and non-Hodgkin lymphoma.<sup>3</sup> Finally, Myeloma is a cancer of the plasma cells, and prevents the normal production of antibodies, limiting the body's immune system.<sup>4</sup>

## **THE LEUKEMIA & LYMPHOMA SOCIETY STORY**

Robert Roesler de Villiers died at the age of 16 in 1944 to leukemia after a brief battle with ineffective treatments. Robert was the son of a wealthy New York family, who, after five years of mourning their son, started a fundraising and education organization in Robert's name. At first, the *Robert Roesler de Villiers Foundation* was small and faced a daunting enemy since most leukemia patients were dying after three months of battling the disease.<sup>5</sup> This organization concentrated on a disease with a 100% fatality rate with a tiny budget and was the predecessor to the Leukemia Society of America. In 2000, the organization transitioned from the Leukemia Society of America to the Leukemia & Lymphoma Society. During the transition, the firm restructured "some of the large metropolitan area chapters to be more responsive to the communities" it served by "centralizing their activities and sharing their resources."<sup>6</sup>

Today, the Leukemia & Lymphoma Society (LLS) is headquartered in White Plains, New York, with a network of chapters in the United States and Canada.<sup>7</sup> LLS is a nonprofit organization that relies on the generosity of individual and corporate contributions to fund research, patient services, professional and patient education, and representation of patients' healthcare concerns and medical research interests to government policy makers.

The firm promotes itself to be the world's largest voluntary health organization dedicated to funding blood cancer research, and also provides education and patient services. Since it was founded in 1949, LLS has invested more than \$750 million in research specifically targeting blood cancers. Additionally, in 2011, LLS made more than 7.1 million contacts with patients, caregivers, and healthcare professionals through its Information Resource Center.<sup>8</sup> Through support and research, the organization has helped to nearly quadruple "the relative five-year survival rate for people with leukemia"<sup>9</sup> and reclassify Hodgkin lymphoma as "one of the most curable forms of cancer."<sup>10</sup>

## **STRATEGIC DIRECTION**

"Nonprofit management is unique because nonprofit organizations are reliant on the support of donors and the work of volunteers, pursuing missions derived from values and principles about which there may be disagreement... among multiple constituencies both inside and outside the walls of the organization itself."<sup>11</sup> In addition, the performance of a non-profit firm's board of directors is measured against the societal mission. Therefore, non-profit executives must manage the double-bottom line of societal and financial performance. This fundamentally differs from businesses that are evaluated against free market forces and aligned by a profit generating value proposition.<sup>12</sup> Exhibit 1 provides a value chain breakdown for LLS.

John Walter joined LLS in 1995 and has been the organization's President and CEO since 2008. He is tasked with achieving LLS's double bottom line. As the Senior Vice President of Finance and Information Technology, he centralized all finance and treasury operations in 1999, leading to a more efficient and stronger organization. "As Executive Vice President of Strategic Alliances and New Business Development, Walter designed and implemented LLS's Co-Pay Assistance Program, a service that helps blood cancer patients with their health insurance premiums and prescription drug co-pays."<sup>13</sup> With over 30 years of experience, he continues to build a strong foundation in his current role of leading LLS. "Walter is stewarding LLS in its efforts to accomplish goals set forth in its strategic plan, including: developing a culture of superior volunteers and staff; diversifying LLS's revenue sources; advancing the development of new blood cancer therapies; and ensuring that all blood cancer patients have access to information and services that help them throughout their cancer journey."<sup>14</sup>

The mission of The Leukemia & Lymphoma Society (LLS) is to "cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families."<sup>15</sup> As the world's largest voluntary health agency dedicated to blood cancer, LLS funds lifesaving blood cancer research around the world and provides free information and support services. Through its mission and list of Key Priorities, The Leukemia & Lymphoma Society helps blood cancer patients live better, longer lives.

LLS's priorities target advancing the societal mission and achieving financial efficiency. In order to advance the diagnosis and treatment of patients with blood cancer, LLS balances resources by prioritizing research, education, and advocacy. Research funding is provided through to academia, the Therapy Acceleration Program, and other special initiatives. Information and services are distributed nationally and locally for patients throughout their cancer journey worldwide. Finally, the Office of Public Policy functions to remove barriers to patient care.

In order for the firm to achieve the greater societal goals, LLS also works towards operational efficiencies in the fundraising, technology, and human resources. It enables its mission by retaining and establishing new income streams across United States and Canada through volunteer engagement and donor pipeline. Priorities for IT include solutions to streamline operations. Lastly, the firm achieves its mission through employee and volunteer talent acquisition and engagement.

## **LLS Boards**

"Non-profit boards are often larger, have more committees, and have a very different board member lifecycle."<sup>16</sup> LLS has three organized boards: Board of Directors (BOD), Medical and Scientific Advisory Board (MSAB) and Board to Trustees (BOT). Each has its own mission and direction that align and support LLS's mission.

"The Board of Directors is the ultimate governing authority of The Leukemia & Lymphoma Society. Its mission is to govern the organization, protect the organization's image and assets, and provide leadership in the fight against blood cancers."<sup>17</sup> Supporting the BOD, there are five standing committees who govern the work of the board and six operating committees who perform "high-level mission-related work and are heavily dependent on volunteers."<sup>18</sup> The BOD

are responsible for the “oversight of LLS’s financial, ethical and legal affairs and ensure the organization’s stability and viability. Approve the annual operating and capital plans as well as monitor progress against goals and program effectiveness, and promote a culture of accountability for results.”<sup>19</sup>

The Medical and Scientific Advisory Board’s responsibility is “to further LLS’s mission by fostering scientific discoveries and medical advances in blood cancers.”<sup>20</sup> The proposed research grants are reviewed by MSAB, which is comprised of volunteer health professionals who are leading experts within their fields. A subcommittee reviews the requests for quality and relevance to the LLS mission. MSAB then creates a funding recommendation based on the overall scientific quality of applications and funds available. The final recommendations are presented to the Mission Oversight Committee for final approval.

The Board of Trustees is based on the local level at each chapter level. The local BOT’s are comprised of volunteers who serve as ambassadors to LLS to help promote events locally, and help recruit sponsors for the organization. “Their mission is in line with the LLS mission, cure leukemia, lymphoma, myeloma and improve the quality of life of patients and their families.”<sup>21</sup>

## **Chapters**

The LLS organizational model is one of a goal seeking system where “the various parts of the association work in coordinated fashion to achieve common system wide goals.”<sup>22</sup> This is a top-down corporate structure in which the chapters rely on the central office to establish an overall plan and to guide organizational actions. Authority can “be delegated from the center to the local members for efficiency reasons” because “all members are assumed to be working in coordinated fashion.”<sup>23</sup>

Branching out from the centralized headquarters, LLS has several local chapters throughout the U.S. and Canada to provide local support and administer local events. Each individual chapter is staffed with a salaried executive director, campaign and services managers, and donor relations personnel to achieve the mission.

The top down strategy at LLS is to assign fundraising and outpatient funding goals to each chapter based on number of participants and number of patients in the area in need of services. Each chapter must meet this fundraising goal while keeping a 75% margin on costs that is used for cancer research, education, advocacy, and patient services.<sup>24</sup> The organization raises this money through numerous fundraising efforts around North America and Canada.<sup>25</sup>

## **Centralized Functions**

LLS has also centralized traditional organization functional groups in human resources, Information Technology (IT), and Finance. Consistent with the organization message, these functional groups strive to do more with less through talent management, technology use, and financial reporting. IT’s mission is to deliver superior services to LLS through its solutions and platforms, and to continue to execute plans in place and find new opportunities to partner with the business units. Human Resources is tasked with hiring, inspiring and retaining "A" talent for

all positions at LLS. One of the goals of LLS is to transform the Human Resources department into a proactive service organization and to strengthen a performance-driven culture. LLS hopes to achieve "best in class" level HR processes from on-boarding to out-placement, and to expand diversity from top to bottom. The Finance department works to minimize labor-intensive transactions and transaction processing, and to greatly reduce staff time spent gathering, consolidating, forecasting and budgeting, actual and operational data. The department also provides analyses and predictive models that help LLS solve problems, gain marketplace advantage, and support new initiatives.

## **Governance Issues**

The non-profit industry is unregulated and unaccountable to outsiders because of light regulation in most states and lack of stockholders. This general lack of oversight can subject firms to agency problems stemming from excessive executive salaries or professional fees associated with operations.<sup>26</sup> However, across the LLS organization, only \$87.9 million in employee salaries and benefits, and \$30.4 million in professional fees, were included in the 2011 consolidated financial statements (See Exhibits 2-3). The disclosure notes indicate that these professional fees include "fundraising counsel fees, data processing services, contracted software development, and legal and auditing fees."

## **REVENUE STRATEGIES**

Fundraisers must develop a funding model to sustain growth and focus the organization to efficiently develop revenue streams. Small organizations may have success with charismatic leadership being the key to "inspiring a handful of donors, seizing unanticipated funding opportunities, or cobbling together a mixed bag of funding sources."<sup>27</sup> However, in order to achieve scale and reach \$50 million in annual revenue, the majority of non-profit organizations "got big not by diversifying their funding sources but by raising most of their money from a single type of funding (such as corporations or government) that was a natural match for their mission. Moreover, they created professional organizations tailored to the needs of that type of funding."<sup>28</sup>

Central to LLS's revenue generation strategies is George Omiros. Omiros has dedicated the majority of his career to LLS, starting in 1988. He took his current position of Executive Vice President of Campaign and Field Development in June of 2012. With almost 25 years of commitment to LLS, George has impacted the organization through various positions such as Executive Director of a local chapter, National Marketing Representative, National Director of Major Gifts, National Director of Community Campaigns and National Director of Federated Campaign. "George now provides strategic direction and overall management of LLS's chapters and their campaign activities, including LLS core campaigns: Team In Training, Light The Night Walk, Man & Woman of the Year and School & Youth programs in the United States and Canada."<sup>29</sup>

## Fundraising

Fundraising is a large organizational function of LLS. Fundraising includes money and time targeting both corporate and individual contributors. LLS's fundraising strategy targets small individual donors by using a heartfelt-connection model through large health-centered events. LLS sponsors many sources to raise money, including: "Team in Training"; "Light the Night Walk"; "Man & Woman of the Year"; "School & Youth Programs"; Leukemia Cup Regatta"; "Make Cures Happen"; and many other golf, BMX, media, and funding events. LLS also partners with corporate sponsors to fund patient programs, license logos, and sell products. Team in Training was created 23 years ago, and it has grown "to be the world's largest and most successful endurance sports charity training program."<sup>30</sup> More than 570,000 people have raised a total of \$1.3 billion participating in the Team in Training program by competing and completing a marathon, half marathon, triathlon, or century ride.<sup>31</sup> Team in Training (TNT) members choose from over 200 accredited international events in which they will compete and raise a requisite amount of money in order to both provide revenue to LLS and cover the team member's event costs.<sup>32</sup> Stakeholders for Team in Training include the sponsors who donate money to the participants, the participants who raise money for the Leukemia and Lymphoma Society, and the recipients of that money raised.<sup>33</sup>

In order to drive commitment and personnel connection, LLS positions its mission through the program. "The Leukemia and Lymphoma Society's Team in Training, for instance, starts each Saturday morning walk or run with a 'dedication.' A cancer survivor, someone who has the disease currently, a researcher, or a Team in Training participant will tell his or her own story before the trainees embark on their exercise session."<sup>34</sup>

Events like races are a positive venue for raising money and condition awareness, while participants are inspired to train harder knowing their event is to raise money for that condition.<sup>35</sup> "Knowing that your increased physical activity could help find a cure for breast cancer, leukemia, arthritis, or some other debilitating...condition certainly helps heighten commitment to an exercise program."<sup>36</sup>

Light the Night Walk funds research and support for cancer patients largely through corporate fundraising teams.<sup>37</sup> The fundraising teams, which can be organized amongst friends, families, and corporations, participate in an evening walk in the fall of each year, and influence millions of consumers to donate at retail outlets across the country.<sup>38</sup>

School & Youth Programs throughout North America organize students in 27,000 registered schools to participate and raise money for smaller programs such as Pennies for Patients, Olive Garden's Pasta for Pennies, HOP for Leukemia & Lymphoma, and the Trish Greene Back to School Program for the Child with Cancer.<sup>39</sup> These organizations have raised \$29 million through the 2011-2012 school year and School & Youth Programs have raised more than \$200 million since its inception.<sup>40</sup>

The Man & Woman of the Year campaign is a ten-week campaign to fundraise for cancer research.<sup>41</sup> The male and female candidates "who raise the most funds during the campaign will be awarded the title of the chapter's Man and Woman of the Year, respectively."<sup>42</sup> The Leukemia Cup Regatta is an annual boating competition held to raise money for cancer

research.<sup>43</sup> Skippers register boats for the event, and recruit friends and colleagues to help crew and to raise funds.<sup>44</sup>

Disconcerting for the Leukemia and Lymphoma Society, “gains of 1.3 million in new and previously lapsed donors were offset by losses of 1.4 million in lapsed donors.”<sup>45</sup> Like many organizations that rely on return donors and participants, the number of donors and volunteers that stay on each year are declining.<sup>46</sup> LLS’s division of Team in Training has had particular trouble in retaining race participants, as it overwhelmingly relies on return participants for its fundraising dollars.

## **Financial Revenues**

Sources of revenue for LLS include contributions, donated services, and investment income. Around 88%, or \$314 million in 2011, of revenue is a result of campaign contributions or donations. External factors can drastically swing the revenue streams from fundraising contributions from year to year. For example, revenue increased 13% between 2010 and 2011, but dropped -4% from 2009 to 2010. Between 2007 and 2011, revenues have increased at a 2.8% annual growth rate.<sup>47</sup>

## **Marketing**

Large organizations possess a fundraising advantage through marketing and positioning. In 2012, the Fundraising Effectiveness Project summarized fundraising effectiveness. One of the findings stated that “Growth-in-giving performance varies significantly according to organization size (based on total amount raised), with larger organizations performing much better than smaller ones. Organizations raising \$500,000 or more had an average 10 percent net gain. Organizations raising \$100,000 to \$500,000 had an average 0.8 percent net gain. Organizations in the under \$100,000 groups had an average net loss of -9.6 percent.”<sup>48</sup> Marketing of the organization is critical for nonprofit revenue generation and competition has even led to some charities taking legal action against other firms regarding messaging. For example Susan G. Komen has protected the phrase “For a Cure” as their own.

In order for charitable organizations to capture market penetration, “word of mouth is, by far, the most frequently cited source of information about charities.” According to Mintel 2009 Charities of Choice Report Survey, 43% of donors “stated that they learned about a charity from a friend or family member while only 14% stated they learned about a charity through an advertisement.”<sup>49</sup> LLS marketing and positioning is focused on grassroots, word-of-mouth efforts and programs to reinforce the mission. The organization does not fund centralized, national marketing campaigns.

## **External Forces Influencing Revenue Generation**

All nonprofits, including cancer societies, are suffering from the recession. “Many organizations continue to experience the effects of the recession, which has resulted in the reduction of badly needed resources.”<sup>50</sup> First, there has been a large increase in the demand for nonprofit services, including for medical services such as cancer treatment and support, as medical patients find themselves unable to pay for expensive treatments and care themselves.<sup>51</sup> Second, donor spending habits are impacted. A study from the Nonprofit Research Collaborative shows that “nonprofits aren’t letting the slower trickle of donations get them down, and 63 percent of organizations surveyed anticipate contributions to them will increase...”<sup>52</sup> There is conflicting research, however whether the nonprofits are able to bolster donations with evidence of increased demand for services, or whether they suffer along with their stakeholders in the midst of a recession.<sup>53</sup>

Nonprofits rely on much-needed donations in the fourth quarter each year, usually a good prospect because the tax year is drawing to a close and the holidays encourage acts of goodwill.<sup>54</sup> “While unemployment stats in recent months have been better than expected, experts predict a difficult end-of-year climate for nonprofits...”<sup>55</sup>

Political factors include the beneficial tax implications for donor groups. The Bush-era tax cuts are expiring and President Obama has mentioned the elimination of charitable giving tax breaks as a viable option for the budget crisis solution.<sup>56</sup> The current structure is framed in the tax code under Charitable Contributions in IRS publication 526.<sup>57</sup> “Qualified organizations include nonprofit groups that are religious, charitable, educational, scientific or literary in purpose, or that work to prevent cruelty to children or animals.”<sup>58</sup> As it is easy to see, the Leukemia and Lymphoma Society falls into a number of these categories, and donors can deduct a lot of their charitable contributions to LLS throughout the year.<sup>59</sup> If charitable deductions are removed from the list of tax deductions taxpayers enjoy each year, the potential outcome for nonprofits such as LLS could be devastating.<sup>60</sup>

Disaster relief efforts also impact the LLS’s fundraising capability. While organizations that deal with disaster relief hopefully see a bump in donations, many of the other causes and issues will see donations pulled away to meet disaster relief needs.<sup>61</sup> Charity transparency is also driving the choice of donor funds. Demand for proof of impact means that younger donors want to see more and more of the impact that their donation will make in an organization.<sup>62</sup> They want to see more robust financial information and an impactful plan of attack from nonprofits.

## **SPENDING STRATEGIES**

Like all businesses, LLS has significant freedom to choose which activities to engage in. In contrast to business entities, non-profit firms do not create value for the firm when satisfying customers, but rather drain captured resources. “Management of a nonprofit organization requires constant trade-offs among the mission, the acquisition of resources, and strategy.” This contrasts with business and public sectors, that “while also complex, at least begins with some fixed points of clear goals and positive relationships between activities and revenues.”<sup>63</sup>



Dr. Louis DeGennaro has a lot of influence over how LLS spends its money. He started his career with LLS in 2005 and has held his current position of Chief Mission Officer since 2010. He has over 25 years of experience in the practice and management of science and has overseen projects that have impacted the lives of patients around the world. “Dr. DeGennaro’s current responsibilities include oversight of all LLS mission functions: Public Policy, Patient Services and Research with the goal of effectively deploying resources in pursuit of the LLS mission.”<sup>64</sup>

## Research

The organization works to proactively establish a research agenda and direct a spending to specific areas of unmet medical needs. LLS participates directly in blood cancer therapy development by enabling research activities by academic collaborations, biotech partnerships, pharmaceutical companies, and venture capitalists. LLS does not perform any scientific activities, but attempts to influence scientific advancement through grants and awards. The corporate office has four research award divisions.<sup>65</sup>

<i>Program</i>	<i>Description</i>
Translational Research Program (TRP)	This program is designed for innovative research with a high promise for advancing from basic biomedical knowledge to clinical application
Specialized Center of Research (SCOR)	This program supports collaborative research across at least 3 integrated projects
Career Development Program (CDP)	This program offers stipends to researchers in order to participate in basic, clinical, or translational research
Therapy Acceleration Program (TAP)	This programs works with corporate partners to enable ‘proof of concept data’ during clinical drug development.

Each research program has separate divisions and strategies within the segment. The TRP, SCOR, and CDP are traditional research grant programs. Grants are initiated by electronic application from an external partner or scholar. Each grant or award request is reviewed by a review panel that is specific for each division. The Medical & Scientific Affairs Committee then reviews the recommendations from each division’s review panel. The Medical & Scientific Affairs Committee then presents a final research portfolio recommendation to the Mission Oversight Committee for approval. The organizational decision making processes are unique for LLS because many of the process decision makers in the division review panels, Medical & Scientific Advisory boards, and Clinical Advisory Committees are comprised of volunteers from academic, healthcare, and corporate organizations. This requires strong mission and values from the corporate office to align strategies of volunteer contributors.

The Therapy Acceleration Program (TAP) serves as a facilitator between discovery and human applications for academic investigators, medical centers, and companies. The goal is to increase the likelihood that novel and breakthrough treatments can be made available to patients sooner.<sup>66</sup> To achieve this end, LLS works directly with corporate sponsors to speed up clinical trials for advancing therapies.

TAP facilitates three innovative levels of research:

- “The *Academic Concierge Division* identifies current LLS funded research with the greatest clinical promise and provides the funding and support needed to advance selected projects to the product stage
- The *Clinical Trials Division* partners LLS with one of the country’s leading clinical-trial centers to accelerate the testing of new blood cancer therapies in clinical trials
- The *Biotechnology Accelerator Division* allies LLS with companies to combine scientific and financial resources and accelerate the development of potential therapies that otherwise would not be prioritized by the company.”<sup>67</sup>

Current partnerships with biopharmaceutical and pharmaceutical companies Baxter, Celgene, and other firms enable faster R&D return on investment. This enables businesses to move therapeutics forward into the marketplace by lowering internal profitability hurdles.

The TAP project-review process “involves due diligence by an LLS staff team of drug development specialists in concert with a volunteer panel of leading biotechnology and pharmaceutical company executives and intellectual property and business development experts.”<sup>68</sup>

### **Patient Education and Services**

Through its different patient services programs, LLS has developed a services agenda for patients, their families, and health professionals to not only address their information and support needs, but also improve access to the latest individual therapy options and blood cancer clinical trials. The programs are both national and local to help patients navigate diagnosis, treatment options, support groups, survivorship, clinical trials, and other matters around the disease specialties.

Below is a summary of the specific resources at the corporate level:<sup>69</sup>

- *Information Specialists* – Available online and over the phone, these masters level oncology professionals provide diagnosis and disease information guidance to patients. They also are able to conduct individual clinical trial searches.
- *TrailCheck* – Through the LLS Website, visitors are able to locate clinical trial opportunities through the blood cancer specific clinical trial search tool.
- *Co-pay Assistance Program* – Patients are able to apply to receive assistance to pay for drug co-pays and health insurance premiums. Applications are handled via website or phone.
- *Telephone and Web Education Programs* – LLS brings together patients, survivors, caregivers, and professionals with this series of educational programs that allows medical experts to share the most current disease, therapy, and research information.
- *LLS Website* – Through the website, visitors are able to access new and archived educational programs, information, and content through a range of electronic formats. Additionally, the venue allows access to support groups, discussion boards, online disease management trackers, and other services and programs.

Below is a summary of the specific resources at the business/chapter level:<sup>70</sup>

- *Family Support Groups* - Volunteer oncology health professionals lead Family Support Groups to encourage communication among patients, families and health professionals.
- *Patti Robinson Kaufmann First Connection Program* – Trained volunteers who are in remission are linked with patients with a similar diagnosis to share information and support.
- *Patient Financial Aid Program* – “For more than 35 years, LLS has helped people who have blood cancer to cover a portion of their treatment costs.”<sup>71</sup>
- *Trish Greene Back to School Program for Children With Cancer* – The program helps children, adolescents, and young adults transition from active treatment and return to school.

Through the Information Specialists, website and local chapters, LLS distributes an extensive collection of free printed educational materials to patients, families, and healthcare professionals.

### **Advocates**

The Office of Public Policy targets government and business decision makers to accelerate development and approval of new treatments and improve care access through equitable insurance reimbursement. This group operates at both the state and national levels. This group is also responsible for driving the LLS mission by increasing funding from non-LLS sources. Both salaried and volunteer employees are utilized.

Through this function, “LLS successfully lobbied Congress in 2001 to institute a blood cancer research initiative as part of the U.S. Department of Defense medical research program. To date, that program has funded over \$30 million in additional blood cancer research. In 2002, LLS successfully lobbied Congress for legislation that authorizes a new blood cancer research effort at the NCI and creates a new blood cancer education program for patients and the public under the Centers for Disease Control and Prevention (CDC). The patient education program was funded at \$32 million through 2011, providing additional support for blood cancer patients and their families nationwide.”<sup>72</sup>

In 2008, a cooperative research and development agreement, called The Learning Collaborative (TLC), between the University of Kansas Medical Center, Kansas City, The Leukemia & Lymphoma Society (LLS), the NIH Therapeutics for Rare and Neglected Diseases (TRND) program and the Hematology Branch within the National Heart, Lung and Blood Institute was “established as a shared commitment to move therapies for rare blood cancers into clinical proof-of-concept studies so that promising treatments can eventually be commercialized.”<sup>73</sup>

### **Charitable Partnerships**

LLS partners with the Alliance for Childhood Cancer, Community Health Charities, Cancer Leadership Council, Friends of Cancer Research, One Voice Against Cancer, and Research!America to find new treatments and cures for blood cancers.<sup>74</sup> These organizations all rely on LLS dollars for research funding and patient care, and in return collaborate with LLS to help achieve LLS’s mission.

## Financial Expenses

LLS expense groups are split between program services, fundraising, and general management. Fundraising expenses and management expenses were 14% and 7% of revenue in 2011. Program services are further split into Research, Patient and Community Service, Public Health Education, and Professional Education.

	2008	2009	2010	2011
Research	28%	25%	26%	24%
Patient and Community Service	28%	33%	31%	37%
Public Health Education	15%	15%	16%	15%
Professional Education	3%	3%	3%	3%
Total Program Services	74%	76%	76%	78%

Program services account for 78% of expenses and, as a measure of fundraising throughput, demonstrates increasing operational efficiency. Organizational salaries and administration expenses are still incurred as part of each of these category functions.

Although the firm spent \$299 Million in 2011, only 22.7%, or \$67.8 Million, was spent on research through awards and grants, and the Therapy Acceleration Program. Although this figure has increased over the last 3 years, it is still below 2007. Within the research budget, money is being shifting away from Awards and Grants and into the Therapy Acceleration Program. In 2011, 25% of research dollars were spent in the program versus 3% in 2009 and 12% in 2010.

The firm's total payments to patients in 2011 were \$43.5 Million through financial aid and co-pay assistance. Patient assistance has varied over the years, but in 2011 was over twice as large as the previous year.

## External Forces Influencing Spending

Demand for nonprofit services has increased over the last four years, but the resources available to those in need are decreasing. This is creating a bottleneck situation that is exacerbated by decreased funding to government social services as well.<sup>75</sup>

Reimbursement for patient care impacts patient access to healthcare services. "2012 will mark the 15th consecutive year that the rate of growth for healthcare spending outpaces U.S. economic growth. For this reason, controlling healthcare costs remains a priority for policy makers, payers, and consumers."<sup>76</sup> Expensive new medical technologies, services, drugs, and medical equipment contribute to the rising costs. "Effective drugs, such as Avastin (from Roche Inc.) and Erbitux (Bristol-Myers Squibb) address previously untreatable lethal cancers, but they must be given over long periods of time and cost tens of thousands of dollars per year."<sup>77</sup>

LLS must depend on the pharmaceutical and biotechnology industries to advance research into commercial solutions. Recently, the brand name pharmaceutical industry profits have been

under pressure from generic drug competition, pricing pressures from payers, and high R&D expenses. At the same time, the industry “has been experiencing a decline in R&D productivity, with a relative dearth of innovative new products launched in recent years.”<sup>78</sup> The industry is counting on improvements in early-stage product pipelines and an aging population to create future revenues and profits.<sup>79</sup>

While the pharmaceutical industry is dedicated to improving patient outcomes, the costs of drug development have become excessive. “Recent estimates of the attrition rate for compounds in oncology range from 77% to 92%, and the average cost of successfully developing a novel therapeutic, when failures are taken into account, is more than \$800 million.”<sup>80</sup> These complex compounds also prolong the development timelines and result in shorter periods of market exclusivity.<sup>81</sup> The industry has responded with retrenchment initiatives, including reorganization of R&D operations. There is receptiveness to “forming alliances and making acquisitions with pipeline considerations in mind.”<sup>82</sup> However, “critics say alliances between non-profit research hubs and Big Pharma give drug companies unfair advantage to research funded by public tax dollars. Exclusive partnerships, they say, allow drug firms to cherry-pick among nonprofit institutes and advance only the drugs with potential profit for them onto the market.”<sup>83</sup>

In order to increase industry collaboration in cancer research within corporations and academia, the government and pharmaceutical industry is working to establish better information sharing mechanisms. The National Cancer Institute’s cancer Bioinformatics Grid™ “initiative is a network of infrastructure and tools that enables the collection, analysis, and sharing of data and knowledge along the entire research pathway from laboratory bench to patient bedside.”<sup>84</sup> In 2008, GlaxoSmithKline released “genomic profiling data for over 300 cancer cell lines” through the Grid in an attempt to enable “other cancer research institutions to save considerable drug development time and capital in their future cancer therapeutic research.”<sup>85</sup>

Unfortunately, with the pharmaceutical industry moving towards collaborative research, intellectual property (IP) issues are being revealed that have not previously existed. “Although certain provisions of the U.S. Federal Acquisition Regulation (FAR) governing federal contracts address IP rights and ownership, the FAR does not clearly address scenarios where both federal and contractor employees work together on a project and are co-inventors of a resulting invention.”<sup>86</sup> In some cases these situations result in expensive lawsuits.

Finally, regulatory hurdles also impact new cancer therapeutics from reaching the market. First, increasing requirements for clinical data delay drug approvals through longer, more detailed processes of generation and agency review. Second, the process itself is not conducive to the multi-therapy treatments that oncology patients are commonly prescribed.<sup>87</sup> Third, regulators further complicate treatment options by limiting use of approved drugs by also regulating marketing approvals.<sup>88</sup>

## INDUSTRY COMPETITION

The U.S. nonprofit industry includes 60,000 organizations with combined annual revenues of \$100 billion.<sup>89</sup> More specifically, the U.S. health fundraising industry consists of about 2,800 organizations with combined annual revenue of about \$16 billion.<sup>90</sup> The 2012 Fundraising Effectiveness Survey Report, part of the Fundraising Effectiveness Project, “shows that the “net gain in giving” for charities responding to the survey in 2011 was \$0”<sup>91</sup> indicating growth in revenue is generated via market penetration.

“The nonprofit and voluntary sector encompasses both professional, paid-staff nonprofit organizations as well as a larger and more diverse population of smaller, informal groups and grassroots organizations.”<sup>92</sup> Major organizations with which, in a broader scope, LLS competes for revenue, include the American Cancer Society, Goodwill Industries, and the Bill & Melinda Gates Foundation.<sup>93</sup> “Included in the industry are grant making foundations, charitable trusts, and other organizations that raise funds for social welfare activities; advocacy organizations that promote a particular cause or benefit a specific constituency; and groups that promote the civic or social interests of their members.”<sup>94</sup> Nonprofits can be classified into service categories, with health as the largest segment of nonprofits, followed by education.<sup>95</sup> For most nonprofits, fundraising is a major activity, as are grant applications, with direct mail solicitation and internet contributions being the two major sources of funds.<sup>96</sup> One of the critical issues that impacts this industry segment is uncertain revenue, because nonprofits do not depend on product sales, and rely instead on the generosity of contributors.<sup>97</sup>

Based on this description, the Leukemia and Lymphoma Society is working in a saturated market with many competitors.<sup>98</sup> From large, formidable cancer organizations like Susan G. Komen and the American Cancer Society to smaller, local organizations like the Heart Connection and Mission4Maureen, LLS is in the peculiar position of having to compete against and work with other cancer organizations for a cure.<sup>99</sup> In 2011, the Leukemia and Lymphoma Society was rated 4<sup>th</sup> for best Cancer Nonprofit organizations, behind Susan G. Komen for the Cure (1), American Cancer Society (2), and LIVESTRONG.org (3).<sup>100</sup>

### **American Cancer Society**

“The American Cancer Society, Inc. (ACS) is the nationwide, community based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer, and diminishing suffering from cancer through research, education, advocacy, and service.”<sup>101</sup> Founded in 1913, it is now the largest voluntary health organization. ACS is dedicated to eliminate cancer by “helping people stay well, helping people get well, by finding cures, and fighting back.”<sup>102</sup> “More than two million volunteers carry out the Society's mission of eliminating cancer and improving quality of life for those individuals facing the disease.”<sup>103</sup>

Headquartered in Atlanta, Georgia, ACS is supported by 12 chartered divisions that have over 900 local offices within those regions. The corporate office is responsive for overall strategic planning, corporate support services, and development and implementation of global and nationwide endeavors.<sup>104</sup> Its local offices are tasked with educating the community, growing

support for programs, and raising money locally. With over three million volunteers, ACS deploys a grassroots marketing campaign depending heavily on the dedication and goodwill of people to gain the support needed. In addition to the \$148.5 million invested in research in 2011,<sup>105</sup> “ACS supports detection, treatment, and education programs. The organization encourages prevention efforts through its Quit for Life antismoking campaign and the International Relay For Life. Patient services include moral support, transportation to and from treatment, and camps for children who have cancer.”<sup>106</sup>

The local chapters are responsible for holding their own programs as well as the national programs. These national programs include spreading awareness through campaigns as well as through athletic events. ACS is recruiting volunteers to get involved in the Cancer Prevention Study – 3 (CPS-3) and through the Great American Smokeout. By far, ACS’s greatest successes in raising money and awareness have been through the athletic events such as Making Strides Against Breast Cancer, DetermiNation, Relay For Life, and Coaches vs. Cancer. These events and other sources generated total revenue of \$953 million in 2011.<sup>107</sup>

### **Susan G. Komen for the Cure**

Founded in 1982, Susan G. Komen for the Cure (SGK) promises “to save lives and end breast cancer forever.”<sup>108</sup> Since its foundation, SGK has invested almost \$2 billion in its search for a cure, including investing over \$685 million in research and \$1.3 billion in community programs.<sup>109</sup> Annual revenues in 2011 were \$438 million.<sup>110</sup> SGK has the support of more than 75,000 volunteers within 120 affiliates with a headquarters in Dallas Texas.<sup>111</sup> With its dedication and contributions, SGK has assisted in earlier detection and effective treatment, more hope, more research and more survivors.<sup>112</sup>

SGK relies on its grassroots efforts to help fulfill its promise of saving lives and ending breast cancer “by empowering people, ensuring quality care for all and energizing science to find the cures.”<sup>113</sup> The global headquarters has been dependent upon its affiliates to help with the successes of its global events. Through events like Komen Race for the Cure, Susan G. Komen 3-Day for the Cure, and Marathon for the Cure, SGK has impacted the lives of not only women but men as well. Its signature event, Komen Race for the Cure, by far its largest event, is hosted on five continents with over 1.7 million participants yearly.<sup>114</sup>

### **Lymphoma Research Foundation**

“The Lymphoma Research Foundation (LRF) is the nation's largest non-profit organization devoted exclusively to funding innovative lymphoma research and providing people with lymphoma and healthcare professionals with up-to-date information about this type of cancer. LRF's mission is to eradicate lymphoma and serve those touched by this disease.”<sup>115</sup> Like many nonprofits, LRF was formed by the merger of two organizations in 2001, Cure for Lymphoma Foundation and the Lymphoma Research Foundation of America. With its focus on finding a cure for lymphoma only, LRF has awarded over \$47 million in research grants. Annual revenues in 2011 were \$11.7 million. To oversee the research grants, LRF has a Scientific Advisory Board with 45 volunteer experts who are also supported by the Board of Directors as well as the Senior Leadership Team. Its annual gala is by far its largest event, but LRF depends

primarily on its 18 chapters and 5,000 volunteers to raise funds and promote its programs and services.<sup>116</sup>

### **Leukemia Research Foundation**

As a direct competitor to LLS, the Leukemia Research Foundation (LeRF) is also attempting “to conquer leukemia, lymphoma, and myelodysplastic syndromes by funding research into their cause and cures, and to enrich the quality of life of those touched by these diseases.”<sup>117</sup> Annual revenues in 2011 were \$1.98 million.<sup>118</sup> Since its foundation in 1946 it has raised over \$52 million with assistance from 23 chapters and over 1,500 volunteers. Working as a smaller foundation, it depends solely on the local chapters to host events to raise awareness and funds with no national events held. To set itself apart LeRF “exclusively funds *New Investigators* - individuals who are beginning to establish their own laboratories and are no longer under the tutelage of a senior scientist mentor.”<sup>119</sup> The research grants are awarded based on the expert recommendations from a Medical Advisory Board. The board bases their recommendations on innovation of the proposal, mission of what affect the study may have and training / environment of the applicant.<sup>120</sup>

## **CONCLUSION**

Born after the death of one sixteen-year-old teenager, the Leukemia & Lymphoma Society is built on goal-setting among chapters and at headquarters. The organization uses sporting events and key fundraising programs to raise millions of dollars for the research of cures for blood cancer and for the patient care of millions of blood cancer victims.

Much like for-profit firms, definition, alignment, and articulation of the organizational mission and values across different internal and external stakeholders is a critical management issue. Strategic implementation demands alignment and accountability of the organization through all the different divisions, chapters, and partners. However, LLS has multiple divisions and offices and heavily relies on volunteers throughout the organization. The fractionalized diverse set of contributors adds complexity to align the workforce and brings unique challenges to oversight and governance. Additionally, the organization’s mission to help patients with blood cancers through support and advancement of treatment options is not conducive to traditional financial measurements.

As in any organization, revenue growth and business efficiency are management priorities. LLS relies on charitable giving of donors and therefore, external forces and industry competition impact the ability to grow existing revenue sources. Positioning and image of the organization itself is critical to revenue generation. Additionally, watchdog organizations continually monitor the effectiveness of organizations’ expenses for revenue generation. While LLS has a traditional fundraising mechanism of using large events to capture campaign contributions, the mechanism for additional revenue generation and growth is a critical strategic issue.

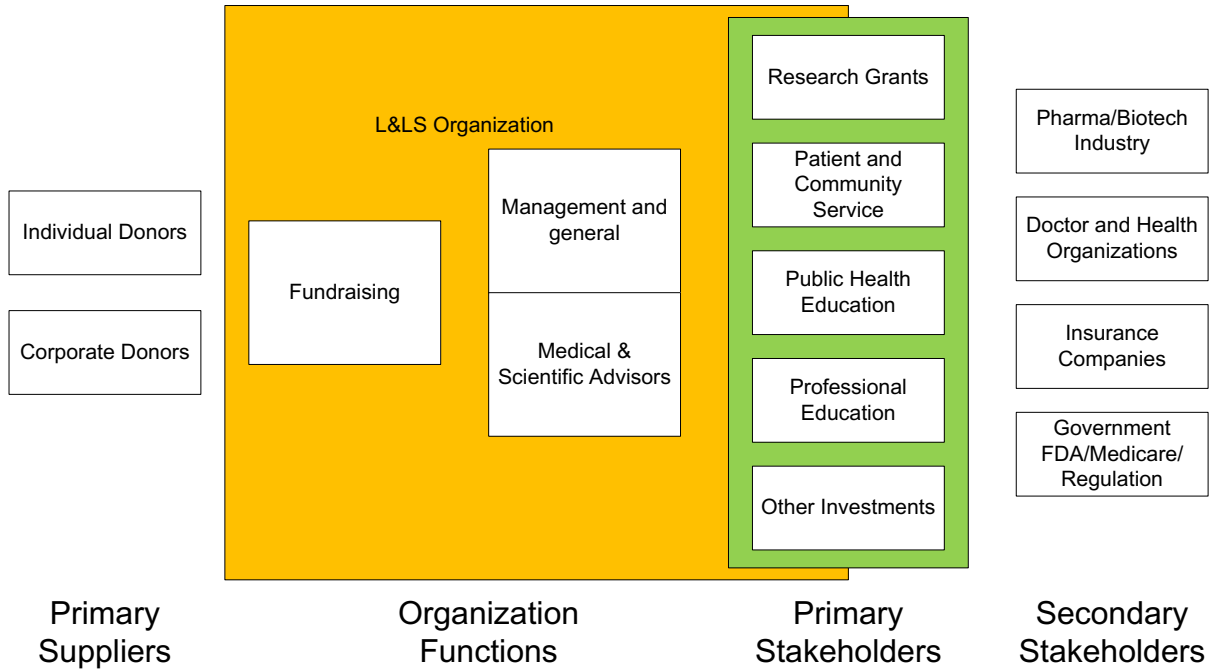
Finally, a key function for LLS is advancing treatment options through research investment. Therefore, return on R&D investment is a critical issue. Much like a pharmaceutical company, LLS must manage the research project portfolio and correctly resource projects that have



promise to reach clinical drug development. However, without internal resources, LLS must not only rely on outside stakeholders to determine which projects to fund, but LLS also relies on external partners to advance projects through the drug development process. Additionally, the large intellectual property value of independent research can lead to isolation of research groups. Therefore, LLS must enable and influence collaboration across research organizations.

# EXHIBIT 1: ORGANIZATION VALUE-CHAIN BREAKDOWN

## Value-Chain Breakdown



**EXHIBIT 2: CONSOLIDATED FINANCIAL STATEMENTS—BALANCE SHEET (000s)**

<b>Assets</b>	2008	2009	2010	2011
Cash and Cash Equivalents	\$36,180	\$28,196	\$21,196	\$17,866
Prepaid Expenses and other assets	\$6,167	\$4,389	\$4,707	\$5,171
Legacies and contributions receivable, net	\$7,167	\$22,752	\$18,417	\$19,614
Investments	\$162,978	\$161,623	\$177,489	\$181,876
Fixed Assets	\$5,148	\$4,616	\$5,132	\$5,413
Depreciation	\$12,069	\$12,544	\$7,965	\$8,606
Amortization	\$10,435	\$12,069	\$12,544	\$7,965
<b>Total Assets</b>	<b>\$217,640</b>	<b>\$221,576</b>	<b>\$226,941</b>	<b>\$229,940</b>
<b>Liabilities and Net Assets</b>				
<b>Liabilities</b>				
Accounts Payable ad Accrued Expenses	\$20,700	\$14,682	\$16,448	\$17,715
Deferred Revenue	\$17,174	\$15,479	\$16,940	\$17,241
Grants Payable	\$81,670	\$85,768	\$80,580	\$71,579
<b>Total Liabilities</b>	<b>\$119,544</b>	<b>\$115,929</b>	<b>\$113,968</b>	<b>\$106,535</b>
<b>Commitments and Contingencies</b>				
<b>Net Assets</b>				
Unrestricted	\$83,085	\$78,551	\$88,617	\$95,108
Temporary restricted	\$11,932	\$23,596	\$20,668	\$24,405
Permanently Restricted	\$3,079	\$2,500	\$3,688	\$3,892
<b>Total Net Assets</b>	<b>\$98,096</b>	<b>\$105,647</b>	<b>\$112,973</b>	<b>\$123,405</b>
<b>Total Liabilities and Net Assets</b>	<b>\$217,640</b>	<b>\$221,576</b>	<b>\$226,941</b>	<b>\$229,940</b>

Source: Leukemia Research Foundation, 2011. **Leukemia Research Foundation Research Grant Funding Making an Impact Annual Report**. Wilmette, IL: Leukemia Research Foundation.

**EXHIBIT 3: CONSOLIDATED FINANCIAL STATEMENTS–INCOME (000s)**

<b>Revenue</b>	2008	2009	2010	2011
Campaign contributions	\$304,380	\$291,521	\$279,908	\$314,044
Less direct donor Benefits	\$(42,541)	\$(39,077)	\$(36,635)	\$(38,070)
Net campaign contributions	\$261,839	\$252,444	\$243,273	\$275,974
Legacies	\$6,137	\$26,459	\$7,054	\$7,736
Donated Services	\$5,740	\$6,829	\$6,819	\$5,983
Net Interest and dividend income	\$7,204	\$6,467	\$4,430	\$2,463
Net increase in fair value of investments	\$(4,839)	\$(7,315)	\$11,335	\$15,283
Grant refunds	\$966	\$2,768	\$1,897	\$1,748
<b>Total revenue</b>	<b>\$277,047</b>	<b>\$287,652</b>	<b>\$274,808</b>	<b>\$309,187</b>
<b>Expenses</b>				
Program Services				
Research	\$76,979	\$69,786	\$70,910	\$71,985
Patient and Community Service	\$77,686	\$93,448	\$83,406	\$109,496
Public Health Education	\$42,094	\$41,331	\$41,597	\$44,197
Professional Education	\$8,433	\$8,497	\$8,073	\$7,979
<b>Total program services</b>	<b>\$205,192</b>	<b>\$213,062</b>	<b>\$203,986</b>	<b>\$233,657</b>
Supporting services				
Management and General	\$24,942	\$23,259	\$22,462	\$23,051
Fundraising	\$46,052	\$43,132	\$41,255	\$42,367
<b>Total supporting services</b>	<b>\$70,994</b>	<b>\$66,391</b>	<b>\$63,717</b>	<b>\$65,418</b>
<b>Total expenses</b>	<b>\$276,186</b>	<b>\$279,453</b>	<b>\$267,703</b>	<b>\$299,075</b>
Foreign Currency translation adjustment	\$37	\$(648)	\$221	\$320
Change in net assets	\$898	\$7,551	\$7,326	\$10,432
<b>Net assets</b>				
Beginning of year	\$97,198	\$98,096	\$105,647	\$112,973
End of year	\$98,096	\$105,647	\$112,973	\$123,405

Source: Leukemia Research Foundation, 2011. **Leukemia Research Foundation Research Grant Funding Making an Impact Annual Report.** Wilmette, IL: Leukemia Research Foundation.

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