



AMERICAN PAIN FOUNDATION®

**American Pain Foundation**  
201 North Charles Street, Suite 710  
Baltimore, MD 21201-4111  
Office (410) 783-7292  
Fax (410) 385-1832  
[www.painfoundation.org](http://www.painfoundation.org)

February 18, 2002

Richard S. Sackler, M.D.  
President  
Purdue Pharma, L.P.  
One Stamford Forum  
Stamford, CT 06901

Re: Report on Our Accomplishments in 2001 and Thank You for 2002 Grant

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Pamela Sutton, MD  
North Broward Hospital District

**Executive Director**

John D. Giglio, MA, JD

Dear Richard:

I would like to thank you for Purdue's continued strong support of the American Pain Foundation. Everyone here was excited to learn of Purdue's generous contribution towards our 2002 activities. I wrote Robin Hogen and Pamela Bennett to thank them for all of their support, but I know that all of their efforts to help us grow would not be possible without your continued belief in what we do here at APF.

I am pleased to submit to you a brief report of our accomplishments in 2001 (attached). I am particularly pleased that in the 12 months since I took over as Executive Director, we were able to grow our staff from 7 to 10 full- and part-time professionals, and nearly double our revenues, which enabled us to serve thousands more people with pain than we did in 2000.

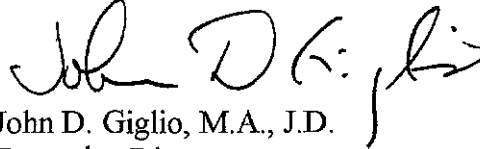
I am also proud that we have continued to diversify our funding base, which is vital if we are to continue growing. My goal is to raise almost \$1 million this year, and thanks to Purdue, we are well on our way. With the addition of a full-time Director of Development in 2001, we have also begun a campaign to develop widespread support from individual consumers and health care professionals who care about improving pain management. This effort will pay a double dividend, because many of these people are also willing to serve as grassroots advocates for our forthcoming federal legislative campaign.

As you may not know, I have hired a superb new Director of Government Affairs who has begun the process of developing comprehensive federal legislation to improve pain management. This is a multi-year process, but we

have gotten off to a very good start. And needless to say, as the former Director of Government Affairs for APF, this is an area where I will maintain a significant role and keep a top priority. I firmly believe that APF is the best-equipped organization in the country to lead this effort.

With that, I am pleased to submit the attached summary of our accomplishments in 2001. With the help of major donors like Purdue, we are already on our way to expanding our efforts to help people with pain in 2002.

Respectfully,



John D. Giglio, M.A., J.D.  
Executive Director

Richard,  
Hope to see  
you again soon.  
-John



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## **2001 Accomplishments**

### **No. 1: Got the Message Out About the Undertreatment of Pain**

In 2001 we were the only consumer-focused pain organization in the country that invested in a full-time Director of Communications and Outreach. Lennie Duensing worked with reporters from TV, radio, newspapers, magazines and the web to educate them about how vast the pain problem is, all with the goal of changing public attitudes.

**TV/Radio/Print/Web Stories:** As a result, our messages have been featured or discussed on CBS News, ABC News, HBO, A&E Network, Good Morning America, *USA Today*, *Wall Street Journal*, *New York Times*, *LA Times*, *Baltimore Sun*, *Boston Globe*, *Chicago Tribune*, National Public Radio, *U.S. News and World Report*, *Better Homes and Gardens*, WebMD, and many others.

**Pain Community News:** We also doubled the circulation of our newsletter, which now runs to 40,000 copies, and produced editions focusing on topics of real interest to pain patients, including complementary/alternative methods of pain management.

### **No. 2: Fought Misconceptions about Opioids in the Press**

Unfortunately for the pain community, stories of abuse of OxyContin and other opioids greatly distorted the public's view of prescription pain medications and threatened to roll back hard won progress for people with pain. We fought this battle on several fronts:

**Media Interviews:** In 2001 we worked with literally scores of journalists, including many from smaller markets who lacked a health background, to fight the misconceptions about opioids. We set up interviews with numerous knowledgeable physicians as well as patients who have benefited from opioids.

**Mass Mailing to Journalists of Our Statement on Opioids:** We crafted a statement on the need for balance in media coverage and policy then mailed it, along with background materials, to over 1,200 health journalists.

**Opioids Section on Web Site:** We created a new Opioids section on our web site with statements from other pain organizations, fact sheets, articles, and up-to-date information on policy action.

**Produced Newsletter on Addiction vs. Physical Dependence:** We devoted one of our newsletters to the APS/AAPMed/ASAM joint statement on addiction vs. physical dependence, and discussed related topics. Our original printing of 40,000 copies ran out so we quickly printed 20,000 more.

**No. 3: Continued Fighting in Washington for Policies to Improve Pain Care**

APF is also the only consumer-focused pain organization with a lobbyist in Washington (or an Executive Director with Hill and lobbying experience, for that matter!). In 2001 we fought on many policy fronts for the rights of people with pain:

**Worked with the DEA on Seeking More Balance:** We were one of the 12 original organizations, which met with the DEA to voice our serious concerns about their approach to investigating diversion and abuse. We led the effort to bring in a panel of pain experts to brief the new Administrator. Another nine groups then joined us in crafting a Consensus Statement with DEA that we presented at a Washington press conference. Two of the five speakers were recommended by APF.

**Submitted Testimony to Congress and the FDA:** APF submitted testimony to the House CJSJ Appropriations Subcommittee that agreed with the DEA on this point: we don't need additional laws but rather more education of health care professionals and DEA field agents on diversion prevention. We also submitted testimony to the FDA opposing several proposed measures, such as centralized pharmacies, that would limit access to opioids by people with pain who were using these medications as appropriately prescribed.

**Issued Grassroots Alerts:** As with the fight against the misnamed *Pain Relief Promotion Act*, we issued several grassroots alerts to thousands of pain patients and health professionals regarding the upcoming actions of the DEA, FDA and Congress.

**Opposed Proposed Medicaid Restrictions:** Although APF does not have the manpower to engage in much state-level policy, we were able to voice our strong concerns about proposals in New Hampshire and Pennsylvania to restrict the legitimate use and access of OxyContin (and by extension, to possibly other opioids) in their Medicaid programs.

**Challenged A.G. Ashcroft's Memo re Controlled Substances:** APF was the first pain organization to challenge the DEA to clarify its intent in implementing Attorney General Ashcroft's memo on the use of controlled substances in assisted suicide. Our *sole* focus was ensuring that DEA action would not inhibit the legal prescribing of these medications for legitimate pain relief.

**Drafted Comprehensive Federal Legislative Pain Mgmt. Proposal:** To build on our success in defeating the misnamed *Pain Relief Promotion Act*, we crafted a comprehensive proposal for legislation to improve pain management built on five principles:

- Investing more federal funding for pain research
- Providing incentives to promote pain management training for health professionals
- Conducting a large national public awareness campaign on pain
- Reducing federal regulatory barriers to pain care, and
- Expanding federal reimbursement for pain medications and treatments

We then began rebuilding and expanding our coalition from 2000 to start focusing on proactive legislation.

**No. 4: Provided Several Free Services to a Much Broader Audience of People with Pain**  
APF's core mission is serving people with pain. In 2001 the number of people we were able to help with free services grew significantly over 2000, thanks to increased financial support.

**Patient Education Materials:** We distributed over half a million free copies of APF patient education materials, including a new Spanish language version of our *Pain Care Bill of Rights*.

**Toll-free Info Line (888-615-PAIN):** We successfully handled a 300% increase in calls to our toll-free info line by expanding our call system technology and adding a new staffer.

**Email Info Service ([info@painfoundation.org](mailto:info@painfoundation.org)):** We also had a 200% increase in inquiries for information and materials via email. Overall, we handled over 4,000 direct requests and inquiries while reducing turnaround time for responses to 24 hours.

**Comprehensive Consumer-focused Web site:** In 2001 we became the only consumer-focused pain organization with a full-time Director of Educational Internet Services. In the past year, she doubled our content, increased the number of visitors to our site by 500%, and won a "Health on the Net Code of Conduct" Seal.

**No. 5: Raised Awareness about Patients' Needs with Allied Organizations**

In the past year, we met with and/or presented talks with over 50 health, medical and patient organizations from around the U.S. on the rights to pain care, how to find help and information, and the need to work together to do more.



Purdue #D # 574  
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**Purdue Pharma L.P.**

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May 2, 2001

Mr. John Giglio  
Executive Director  
American Pain Foundation  
1111 S. Calvert Street - #2700  
Baltimore, MD 21202

Dear John:

Congratulations on your appointment as Executive Director of the American Pain Foundation! While Jim Guest leaves big shoes to fill, I know you are up to the challenge. As you assume this important new role, I want you to know you have the full and enthusiastic support of Purdue Pharma. We were rooting for you all the way, John, and we are delighted that you got the gold ring!

It is my pleasure to enclose herein a \$100,000 contribution from Purdue Pharma L.P, representing the first installment on our \$250,000 challenge grant for 2001. We understand you have already secured gifts totaling over \$100,000 from other corporate funders this year, for which this is the matching grant.

We will send additional installments, up to a total of \$250,000, once you confirm in writing that the APF has written pledges in hand for the balance of this challenge grant. We hope this has been a useful point of leverage in your development efforts.

Please accept this grant with my best wishes for every success in your new role at the APF. I would appreciate a call before the end of the week so we can discuss your plans for the Stop Pain Now Campaign.

Sincerely,

Robin Hogen  
Executive Director

Enclosure: Check # 66546

cc: Dr. Richard Sackler  
Michael Friedman  
Pamela Bennett

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BALTIMORE, MD 21202

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September 19, 2002

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American Cancer Society  
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Beth Israel Medical Center

**Executive Director**

John D. Giglio, MA, JD

Pamela Bennett  
Director of Advocacy, Public Affairs  
Purdue Pharma, L.P.  
One Stamford Forum  
Stamford, CT 06901

Re: Report on Our Accomplishments in 2002 and  
\$250,000 Grant Request for 2003

Dear Pam:

On behalf of my board, staff and Scientific Advisory Committee, I wish to thank you and Purdue for your extremely generous educational grant of \$250,000 last year, along with the seed grant to launch PainAid, our on-line forum (which has been built, fully staffed, and is the final "shake down" testing phase as this is being written).

I am pleased to submit this report of our accomplishments in 2002 to-date and a grant request of \$250,000 for 2003. **In 2002, Purdue was still our largest donor**, but because we expanded our donor base, we were able to do more for patients. After reviewing our accomplishments, I hope you will agree that the results we've achieved, the team we've built, the growth we've undergone, and the projects we have underway for 2003 demonstrate the value of your previous contributions and continued support of the American Pain Foundation.

In the meantime, you will also be interested to know that my board plans to discuss the idea Robin suggested of an Industry Sponsors Annual meeting during our upcoming board meeting.

Sincerely,

/s/

John D. Giglio, M.A., J.D.  
Executive Director

cc: Robin Hogen  
Jeannette Doné





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## **Report to Purdue on 2002 Accomplishments and 2003 Grant Request**

### **Overview**

Thanks to Purdue, our single largest supporter, and a growing number of other grantors and contributors, the American Pain Foundation has become the largest, most effective, fastest growing, and most active consumer pain organization. With 13 full- and part-time staff, and 24 full- and part time program volunteers, we have been able to serve more consumers than any other such group because we are the only organization of our kind to offer a full range of services, programs and advocacy activities:

- ⇒ **Website:** Comprehensive site designed for consumers ([www.painfoundation.org](http://www.painfoundation.org))
- ⇒ **Email Info Service:** Pain sufferers can get answers to specific questions submitted via email ([info@painfoundation.org](mailto:info@painfoundation.org))
- ⇒ **Toll-free Info Line:** Consumers not on the web can call for information toll-free(1-888-615-PAIN)
- ⇒ **Education Materials:** Broad range of printed materials written at the layperson level
- ⇒ **Media Relations and Public Awareness:** Direct work with national, regional and specialty journalists in print, TV, and radio through a full-time Communications Director
- ⇒ **Federal Legislative Advocacy:** Established leadership in federal legislative lobbying via our Washington-based Director of Government Affairs
- ⇒ **Newsletter:** Regular printed newsletter for patients (*Pain Community News*)
- ⇒ **New! On-line Interactive Forum:** Extensive on-line interactive forum for patients run 24/7 by 28 volunteers & staff (*PainAid*)
- ⇒ **New! Monthly E-Newsletter:** Nation's 1<sup>st</sup> free monthly e-newsletter focusing exclusively on the needs of pain patients
- ⇒ **Coalition Leadership and Alliance-Building:** Building coalitions and alliances by personally meeting with every major pain group and key stakeholders

Last year, APF served an estimated 1 million consumers. With the addition of new services, more program staff, greater visibility, and greater financial support, APF moved up to "the next level" as an organization this year. And we are proud to report that we are on track to significantly exceed last year's service mark of 1 million this year.

But we remain tiny by comparison to other consumer-based organizations like the American Diabetes Association, National Kidney Foundation and the National Breast Cancer Coalition, even though serious chronic pain afflicts more Americans than diabetes, kidney failure and breast cancer combined.

With a world class board of directors and Scientific Advisory Committee, highly experienced staff, assertive leadership, a full range of services, skilled lobbying and media professionals, and a growing and more diversified funding base, APF is poised to take another step up in 2003.

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## **Report on 2002 Accomplishments**

### **Introduction**

We are pleased to submit this summary of our accomplishments to date in 2002, which were made possible by support from over a dozen corporations and foundations, led by Purdue Pharma, and hundreds of individuals.

### **Got the Message Out About the Undertreatment of Pain**

In 2002 APF was again the only consumer-focused pain organization that invested in a full-time Director of Communications and Outreach. Through the first three quarters of 2002, Lennie Duensing, M.Ed., worked with reporters from TV, radio, newspapers, and magazines to educate them about how vast the pain problem is, all with the goal of changing public attitudes.

**TV/Radio/Print:** As a result, our messages have been featured on WJZ-TV (an ABC affiliate), HBO, GQ Magazine, *Salt Lake Tribune*, *Pittsburgh Business Times*, *Tallahassee Democrat*, *Business Dateline*, *Gainesville Sun*, *Tufts Univ. Health and Nutrition Letter*, *Cincinnati Business Courier*, and in a Canadian television segment.

**AARP's *Modern Maturity*:** After over a year of work, we placed a major story in AARP's flagship magazine *Modern Maturity*, the nation's largest subscription-based magazine with over 7 million readers. This was AARP's first major story on pain in the elderly in recent memory, and it resulted in a 200% increase in calls to our toll-free info line.

**Daylong Pain Workshop for Health Journalists:** APF was invited to present the first-ever daylong "intensive" workshop on pain for health journalists at the annual meeting of the Association of Health Care Journalists. Our program included APF Scientific Committee

Members Dr. Frank Keefe and Dr. Mitchell Max, along with Melanie Thornstrom of the New York Times, Dr. Peter Staats, APF Consultant Micke Brown, R.N., and two pain patients.

**APF's *Pain Community News*:** The circulation of our printed newsletter continues to grow and now runs to 40,000 copies. We have produced editions focusing on topics of real interest to pain patients, such as how to find a pain specialist.

### **Fought Misconceptions about Opioids in the Press and with Allied Groups**

Unfortunately for the pain community, stories of abuse of OxyContin and other opioids greatly distorted the public's view of prescription pain medications and threatened to roll back hard won progress for people with pain. We fought this battle on several fronts:

**Testified at FDA Hearing:** John Giglio was the first of several public witnesses at the two-day January FDA hearing on opioids to testify about the value of this class of medications.

**Submitted Testimony at Senate Health Committee Hearing on OxyContin:** Our Executive Director submitted more extensive remarks to this Senate Committee that urged Congress not to pass any additional legislation regulating opioids, either individually or as a class.

**Presented "*Are Pain Patients Becoming Collateral Damage on the War on Drugs?*":** John likewise presented a comprehensive talk on recent regulatory, legislative and legal activity on opioids to several professional audiences, including the American Society of Consultant Pharmacists, Association of Health Care Journalists, American Society of Pharmacy Law, and Pri-Med Atlantic (planned.)

**Advised Mayor Giuliani and Purdue on Plan for *Rx Action Alliance*:** After meeting with the Mayor, John advocated substantial changes to the structure and approach of the proposed coalition. This generated a significant amount of debate and, to the company's and Mayor's credit, resulted in changes that several of the other proposed nonprofit partners found reassuring.

**Opposed Proposed Medicaid Restrictions:** Consistent with our previous letters to the New Hampshire and Pennsylvania Medicaid programs, we wrote Delaware Medicaid to oppose any preauthorization or other additional restrictions on opioids.

**Media Interviews:** In 2002 we continued working with journalists, including many from smaller markets who lacked a health background, to fight the misconceptions about opioids. We set up interviews with numerous knowledgeable physicians as well as patients who have benefited from opioids.

## **Made Surprisingly Quick and Major Progress in Washington Promoting Legislation to Improve Pain Care**

APF is the only consumer-focused pain organization with a lobbyist in Washington (or an Executive Director with Hill and lobbying experience, for that matter). Over the last 15 years, Congress has never seriously considered a single proposal to improve pain management. That is about to change. In just the last nine months, we have made surprising progress on three separate fronts to change federal policy on pain care.

### **Added Major Pain Management Provisions to Kennedy-Frist Cancer Bill (S. 2965):**

When Senator Kennedy, chair of the Health Committee, teamed with Senator Frist, the Republican chair of the Public Health Subcommittee, to work on a cancer bill, we knew that their proposal would garner major support. APF immediately formed and led a small group of pain experts to fight for substantive pain initiatives. After working intensively with Senate staff for 10 months, we have achieved a precedent: the first serious cancer bill to contain major pain management provisions. They include educating health professionals, conducting public awareness and outreach campaigns, changing training curricula, addressing the needs of underserved populations, and more. As this is being written, the bill is moving toward consideration by the full Senate.

### **Placed Significant Pain Care Initiatives in Gregg-Brownback Cancer Bill (S. 2955):**

To our surprise, Senator Gregg (R. N.H.), ranking Republican on the Senate Health Committee, and Senator Brownback (R. Kan.), teamed up on a *second* cancer bill. Again, APF led an intensive effort to add initiatives to improve cancer pain management training and public awareness to their bill. We also inserted a section calling for an evaluation of how Medicare reimbursement rates impact pain management, and helped win language adding pain management research to NCI's mission.

### **Developed Comprehensive Federal Pain Mgmt. Proposal and Started Coalition:**

As we work to pass these cancer pain proposals, we hope they will open the door for Congress to consider a broader proposal that would improve pain management for all non-malignant conditions. In collaboration with the American Pain Society and the American Academy of Pain Medicine, APF has begun organizing a coalition of physicians, nurses, pharmacists and patient groups in D.C., held several meetings, and laid the groundwork to recruit over 70 groups. Our proposal has been expanded and refined, and addresses six major needs.:

1. Research
2. Training
3. Public Awareness
4. Regulatory barriers
5. Reimbursement
6. Standards of care

## **Provided Range of Free Services to a Larger Audience of Patients**

APF's core mission is serving people with pain. In 2002 the number of people APF has helped to date with our free services has grown significantly over 2001.

**Patient Education Materials in English and Spanish:** We have distributed hundreds of thousands of free copies of our current patient education materials, and expanded the network of organizations that are using them. We have a new major piece on How to Find a Specialist in final draft form, and have received the funding to translate it and two other major items into Spanish.

**Toll-free Info Line (888-615-PAIN):** We have handled a 200% increase in calls to our toll-free info line since the beginning of the year.

**Email Info Service (info@painfoundation.org):** We have also experienced a 150% increase in inquiries for information and materials via email. Overall, we have handled over 3,000 direct requests and inquiries while reducing turnaround time for responses to 24 hours.

**Comprehensive Consumer-focused Web Site (www.painfoundation.org):** In 2001 we became the only consumer-focused pain organization with a full-time Director of Education & Internet Services, Yvette Colón, M.S.W. In the past year and a half, she has expanded our content and features; added a complementary and alternative section, increased the number of organizations we link to, raised the number of visitors to our site from 13,000/month to 45,000/month, and won a "Health on the Net Code of Conduct" Seal.

**APF at Top on the Web:** In a genuine tribute to the quality and visibility of our website, of the 13.1 million web sites the search engine Google brings up when "pain" is searched, the American Pain Foundation is now No. 3!

## **PainAid: APF's New On-line, Interactive Forum for Pain Patients**

Thanks to a \$25,000 seed grant from Purdue, APF is ready to launch the nation's only comprehensive, moderated, on-line interactive forum for pain patients, called *PainAid*. We have:

- ☐ Built the site,
- ☐ Recruited three paid staff and 24 full- and part-time volunteers,
- ☐ Set up 76 message boards on virtually all major pain topics,
- ☐ Established two major chat rooms,
- ☐ Scheduled up to four regular chats per day, and
- ☐ Recruited 10 experts to staff our Ask-the-Expert program.

As this is being written, we are completing testing. We also just received an 18-page(!) risk management plan from our law firm, which we are in the process of implementing. Given the labor-intensity of this project, however, we have completed a detailed, three year budget and were a bit overwhelmed to see that it will take over \$200,000/year to run *PainAid*. Given that this is only such service offered in the U.S., we are committed to finding the resources to keep it running and add three proposed new features (discussed in the grant proposal that follows).

### **Pain E-News: APF's New Monthly Electronic Newsletter**

Thanks to a two-year, \$200,000 grant from the Medtronic Foundation (the largest grant given to a patient group this year), we have recruited the staff, built the template, and are just two weeks away from launching the only pain electronic newsletter targeted at consumers. With the addition of Carol Harper, M.A, as Manager of Consumer Information, we have a highly experienced writer and editor who will lead this project, and we expect circulation numbers to build quickly.

### **Reached Out to All Major Pain Groups and Allied Organizations and Positioned APF as a Leading Advocate for Pain Patients**

APF has become a leader in building alliances and developing collaborations by personally reaching out to key stakeholders in three ways:

**Meeting with Nearly All Leading Pain Groups:** In just the past 9 months, APF has been the only pain organization to personally meet with the boards of directors and/or Executive Directors of nearly every key pain organization and discuss collaboration opportunities and strategies, including:

- American Academy of Pain Management
- American Academy of Pain Medicine
- American Academy of Physical Medicine and Rehabilitation
- American Alliance of Cancer Pain Initiatives
- American Cancer Society, Pain Management Project
- American Chronic Pain Association
- American Headache Society
- American Pain Society
- American Society of Pain Management Nurses
- International Association for the Study of Pain
- National Foundation for the Treatment of Pain
- National Pain Foundation
- Pain & Policy Studies Group
- Pain Care Coalition

**Serving on the Boards of Allied Organizations:** APF staff serve on the boards of many important allies, including:

- ⇒ American Alliance of Cancer Pain Initiatives
- ⇒ Association of Oncology Social Workers
- ⇒ Community-State Partnerships for End-of-Life Care
- ⇒ Intercultural Cancer Council
- ⇒ Maryland Pain Initiative
- ⇒ National Council on Aging

**Collaborating with Other Key Stakeholders:** Finally, in just the past nine months APF staff have collaborated closely on pain management issues with host of key groups, including:

- AARP
- American Academy of Family Physicians
- American Geriatrics Society
- American Nurses Association
- American Pharmaceutical Association
- American Society on Aging
- Hospice and Palliative Nurses Association
- Joint Commission on Accreditation of Health Care Organizations
- Last Acts
- National Association of Social Workers
- National Association of Orthopedic Nurses
- National Hospice and Palliative Care Organization
- Oncology Nursing Society
- Project on Death in America

### **Increased Our Financial Resources to Serve Patients**

Overall, APF continues the growth pattern we started five years ago and believe we have become the largest, fastest-growing, most effective, and most active national organization serving people with pain. Specifically, we:

**Increased and Diversified Revenues:** So far in 2002 we have seen a significant expansion in APF's resources, and thus our ability to help consumers. From a \$395,000 budget two years ago, we grew to \$771,000 in 2001, and we are on target to raise \$1.0 million this year. This could not have been possible without the generous support of Purdue, nearly a dozen other companies and foundations, and hundreds of individuals.

**Launched Quarterly Individual Donor Campaign:** After hiring a full-time Development Director, we launched our first-ever direct mail campaign to 17,000 individuals. Our aim is to expand our donor base, and we are on track to complete four quarterly appeals this year. While we must spend the capital for start up costs for this individual donor campaign, we are confident that the investment will pay off.

**Established an Endowment Fund:** To build for the future, we have established an endowment fund equal to nearly one year's revenues. We believe we are the only consumer-focused pain organization to have such a fund.

**Begun Cultivating Foundations and Major Individual Donors:** APF's long-term financial goal is to convert to a predominantly consumer-and foundation-supported organization. In that vein, we are pleased to report that Amy Myers, APF's former Director of Development, has rejoined us part-time and will focus on writing foundation grants. We have also begun a modest major donor cultivation plan.

**Reducing Purdue's Share of Our Annual Budget:** Regarding Purdue's portion of our total support, it has decreased each year since 1998, and will decrease again in 2003 as we continue diversifying our revenues.

### **Achieved High Marks for Fiscal Responsibility**

As in previous years, we received a clean audit last year from our outside auditors and expect to continue this track record. At the same time, we have cut our administrative and fundraising costs from 25% to (est.) 13%. In addition we:

**Held First Open House for Donors:** This year we became the first (and as far as we know only) consumer pain organization to open its doors to all of its major donors and hold an open house. Similarly, we believe we were the first consumer-based pain group to issue an Annual Report and distribute over 5,000 copies to donors and key individuals.

**Invited to Join the *Combined Health Charities of Maryland*:** Finally, we are proud to report that we have been invited to become one of only 24 health charities who qualify to receive employer-sponsored donations through the Combined Health Charities of Maryland, a partner of the United Way. We are joining an elite group that includes the American Heart Association, American Cancer Society, and several other leading health nonprofits.

### **Expanded Program Staff and Diversified our Board**

With increased revenues, we expanded our paid program staff from 10 to 13 full- and part-time professionals and built a corps of 24 full- and part-time volunteers. At the same time, we diversified our board by adding a pain patient (who is also a banker), a nurse (who is also a nonprofit group executive), and a representative from the American Academy of Pain Medicine's board (Dr. Scott Fishman, who has a special interest in consumer education.)

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## **Grant Request of \$250,000 for 2003**

The American Pain Foundation requests an unrestricted educational grant from the Purdue Pharma Fund of \$250,000 to support the following key patient-education programs, media advocacy work, and public policy leadership efforts:

### **Expand Our Three Established Patient Education Services**

Because of our increased visibility and successful public outreach efforts, requests for assistance from patients has grown tremendously in the past year, and we expect that growth rate to continue, if not accelerate. To keep up with consumer demand, we must expand our Patient Education Department to handle this increased load. Specifically, we need support for our three established patient education services:



- 1) **Provide Additional Expertise to Reply to Complex Inquiries via our Email Info Service:** Emails from patients have not only increased in volume but also in complexity as more people with very serious pain problems learn about us. We need to increase the number of hours our paid Pain Management Advisor can spend handling these complex problems. At the same time, we will begin referring less difficult issues to the 76 pain-related message boards and Ask-the-Expert service we have on *PainAid*.
- 2) **Handle Increased Volume of Calls to our Toll-free Info Line:** Despite the increasing percentage of consumers who are on-line, a significant portion of Americans, especially the elderly and the poor, will continue to rely exclusively on our toll-free info line to get information and help. We must add the equivalent of a ½ FTE to handle the larger load.
- 3) **Expand Our Web Site:** The quality and quantity of the information on our web site has gone up every year since its launch in 1998, but we still have much work to do. We must add Spanish-language content and culturally-relevant content for other under-served populations. We must add information useful for those impacted by a patient's suffering, including caregivers and families. We must provide more up-to-the-minute information on critical financial issues, including insurance, workers' compensation, managed care, Medicaid, Social Security Disability, Medicare and related issues. And more.

### **Support our Highly Effective Media Relations and Public Awareness Work**

Not only is Lennie Duensing, M.Ed., the only full-time communications professional working for a consumer-based pain group, she is one of the best media relations directors working among all health nonprofits. Her work has helped raise awareness about pain among the general public. During all that time, she has carefully cultivated a wide range of journalists. Moreover, she has trained a corps of physicians, nurses and patients to speak effectively with the media. Equally important, she has demonstrated how vital media relations are in policy advocacy and generating grassroots action, which will be critical during the upcoming Congressional session. We need to continue having success with the media to advance the cause of better pain care.

### **Underwrite Three Expansion Projects for *PainAid*, APF's On-line Patient Program**

*PainAid* is by far the most comprehensive on-line services program for pain patients in the U.S. However, similar programs provided by cancer and other disease groups offer several important, needed features to assist their patients which we lack, but which our patients deserve. Within the first nine months of *PainAid's* operation, we hope to add:

- 1) **Physician Finder** – Using selection criteria we develop in consultation with our Board of Directors and Scientific Advisory Committee, we will provide patients nationwide with an easy-to-use feature that allows them to identify qualified pain management specialists in their local area.

- 2) **Pain-in-the-News** – To encourage repeat visits to *PainAid* and build an on-line community, we will offer visitors, upon logging on, recent news and other media reports on new developments, treatment options, and more. As with the Physician Finder, we will develop the criteria for selecting stories in consultation with the APF Board and Scientific Advisory Committee.
- 3) **PainAid Resource Library** – We are committed to providing users with a simple-to-use library of downloadable materials that includes logs from guest speaker chats, fact sheets, other patient education content, and access to a database of information on prescription and over-the-counter medications. As with the above projects, the criteria for selecting the materials to be included in our library will be developed solely by APF.

We project that the cost of developing and launching these three projects at \$75,000. Annual operating costs for *PainAid* will be nearly double that. Therefore, we are committed to seeking underwriting from other funders for the annual operating costs, and hope that Purdue can target its contribution to enabling us to add these three new services.

### **Help Us Continue Leading the Federal Legislative Advocacy Effort in Washington**

Using unrestricted donations from a variety of sources, including corporate grantors like Purdue, we hope to build on our quicker-than-expected initial successes to get major portions of our proactive pain management legislative agenda moving in the U.S. Senate. As the only consumer-based pain group in the U.S. with a Washington lobbyist, our continued leadership in this arena is critical, because the road to final passage contains a host of obstacles and challenges.

And although this is a multi-year effort, our Executive Director and Board are absolutely committed to keeping legislative advocacy a core mission of the American Pain Foundation, because it has the potential to make a *major*, long-lasting difference in the lives of millions of Americans in pain.

Though quite detailed, our legislative agenda revolves around six basic principles:

- Issue Area 1:* Conduct a National Public Awareness Campaign on Pain Management and How to Get Help
- Issue Area 2:* Provide Federal Support for Professional Training in Pain Management
- Issue Area 3:* Reduce Regulatory Barriers to Pain Management
- Issue Area 4:* Increase Federal Support for Pain Management Research
- Issue Area 5:* Expand Federal Reimbursement for Pain Care Treatments and Services
- Issue Area 6:* Require Proper Pain Assessment and Treatment in Federally Supported Programs and Facilities

## **Conclusion**

APF has a demonstrated record of quality patient service, leadership, collaboration, and growth. We are proud that our campaign to raise \$1.3 million for 2003 is already underway. We remain extremely grateful for Purdue's early confidence in us and hope that we have earned your renewed support.

9/19/02 -- PP/JDG



AMERICAN PAIN FOUNDATION®

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February 1, 2002

Robin Hogen  
Executive Director, Public Affairs  
Purdue Pharma, L.P.  
One Stamford Forum  
Stamford, CT 06901

Re: Report on Our Accomplishments in 2001 and \$250,000 Grant Request for 2002

Dear Robin:

I am pleased to submit this report of our accomplishments in 2001. I also hope you agree that the results we've achieved since I took over last January, the team I have put in place, and the projects we have underway for 2002 make a strong case for Purdue's renewal of its \$250,000 unrestricted educational grant to support all of our patient-focused services.

As was the case last year, I think conditioning your grant on my raising an additional \$250,000 in matching funds serves both of us well. It ensures that your continued investment in APF will be highly leveraged, and it provides tremendous incentive for me to continue diversifying our funding base. To that end, allow me to summarize where we are financially.

Overall, 2001 saw significant growth in APF's resources, reach, activities and impact. I increased revenues from \$395,000 in 2000 to just under \$800,000 in 2001 and expanded our staff from 7 to 10 full and part-time professionals. With the generous support from companies like yours as well as several foundations and many individuals, we successfully increased our production in each of our strategic missions.

We plan to do even more in 2002, and I am well on my way to raising my goal of over \$900,000. I have already received grant awards totaling \$170,000 as of January 31st. Equally important, with my hiring of a full-time Director of Development several months ago, we have launched our first major direct mail campaign targeted at individual donors. My long-term goal is to convert APF to a predominantly consumer-supported organization. In the near-term, however, we have to spend the capital for start up costs for this fundraising effort (e.g. database, mailing lists, donor acquisition), but I am confident that this investment will pay off. Regarding Purdue's portion of our total support vs. expenses, it has decreased each year since 1998, and will decrease again in 2002 to less than 29%.

With that, I am pleased to report on our accomplishments in 2001, and follow that with a summary of the programs and projects we plan to implement in 2002 with your support.

## **2001 Accomplishments**

### **No. 1: Got the Message Out About the Undertreatment of Pain**

In 2001 we were the only consumer-focused pain organization in the country that invested in a full-time Director of Communications and Outreach. Lennie Duensing worked with reporters from TV, radio, newspapers, magazines and the web to educate them about how vast the pain problem is, all with the goal of changing public attitudes.

**TV/Radio/Print/Web Stories:** As a result, our messages have been featured or discussed on CBS News, ABC News, HBO, A&E Network, Good Morning America, *USA Today*, *Wall Street Journal*, *New York Times*, *LA Times*, *Baltimore Sun*, *Boston Globe*, *Chicago Tribune*, National Public Radio, *U.S. News and World Report*, *Better Homes and Gardens*, WebMD, and many others.

**Pain Community News:** We also doubled the circulation of our newsletter, which now runs to 40,000 copies, and produced editions focusing on topics of real interest to pain patients, including complementary/alternative methods of pain management.

### **No. 2: Fought Misconceptions about Opioids in the Press**

Unfortunately for the pain community, stories of abuse of OxyContin and other opioids greatly distorted the public's view of prescription pain medications and threatened to roll back hard won progress for people with pain. We fought this battle on several fronts:

**Media Interviews:** In 2001 we worked with literally scores of journalists, including many from smaller markets who lacked a health background, to fight the misconceptions about opioids. We set up interviews with numerous knowledgeable physicians as well as patients who have benefited from opioids.

**Mass Mailing to Journalists of Our Statement on Opioids:** We crafted a statement on the need for balance in media coverage and policy then mailed it, along with background materials, to over 1,200 health journalists.

**Opioids Section on Web Site:** We created a new Opioids section on our web site with statements from other pain organizations, fact sheets, articles, and up-to-date information on policy action.

**Produced Newsletter on Addiction vs. Physical Dependence:** We devoted one of our newsletters to the APS/AAPMed/ASAM joint statement on addiction vs. physical dependence, and discussed related topics. Our original printing of 40,000 copies ran out so we quickly printed 20,000 more.

**No. 3: Continued Fighting in Washington for Policies to Improve Pain Care**

APF is also the only consumer-focused pain organization with a lobbyist in Washington (or an Executive Director with Hill and lobbying experience, for that matter!). In 2001 we fought on many policy fronts for the rights of people with pain:

**Worked with the DEA on Seeking More Balance:** We were one of the 12 original organizations which met with the DEA to voice our serious concerns about their approach to investigating diversion and abuse. We led the effort to bring in a panel of pain experts to brief the new Administrator. Another nine groups then joined us in crafting a Consensus Statement with DEA which we presented at a Washington press conference. Two of the five speakers were recommended by APF.

**Submitted Testimony to Congress and the FDA:** APF submitted testimony to the House CJSJ Appropriations Subcommittee that agreed with the DEA on this point: we don't need additional laws but rather more education of health care professionals and DEA field agents on diversion prevention. We also submitted testimony to the FDA opposing several proposed measures, such as centralized pharmacies, that would limit access to opioids by people with pain who were using these medications as appropriately prescribed.

**Issued Grassroots Alerts:** As with the fight against the misnamed *Pain Relief Promotion Act*, we issued several grassroots alerts to thousands of pain patients and health professionals regarding the upcoming actions of the DEA, FDA and Congress.

**Opposed Proposed Medicaid Restrictions:** Although APF does not have the manpower to engage in much state-level policy, we were able to voice our strong concerns about proposals in New Hampshire and Pennsylvania to restrict the legitimate use and access of OxyContin (and by extension, to possibly other opioids) in their Medicaid programs.

**Challenged A.G. Ashcroft's Memo re Controlled Substances:** APF was the first pain organization to challenge the DEA to clarify its intent in implementing Attorney General Ashcroft's memo on the use of controlled substances in assisted suicide. Our *sole* focus was ensuring that DEA action would not inhibit the legal prescribing of these medications for legitimate pain relief.

**Drafted Comprehensive Federal Legislative Pain Mgmt. Proposal:** To build on our success in defeating the misnamed *Pain Relief Promotion Act*, we crafted a comprehensive proposal for legislation to improve pain management built on five principles:

- Investing more federal funding for pain research
- Providing incentives to promote pain management training for health professionals
- Conducting a large national public awareness campaign on pain
- Reducing federal regulatory barriers to pain care, and
- Expanding federal reimbursement for pain medications and treatments

We then began rebuilding and expanding our coalition from 2000 to start focusing on proactive legislation.

**No. 4: Provided Several Free Services to a Much Broader Audience of People with Pain**

APF's core mission is serving people with pain. In 2001 the number of people we were able to help with free services grew significantly over 2000, thanks to increased financial support.

**Patient Education Materials:** We distributed over half a million free copies of APF patient education materials, including a new Spanish language version of our *Pain Care Bill of Rights*.

**Toll-free Info Line (888-615-PAIN):** We successfully handled a 300% increase in calls to our toll-free info line by expanding our call system technology and adding a new staffer.

**Email Info Service (info@painfoundation.org):** We also had a 200% increase in inquiries for information and materials via email. Overall, we handled over 4,000 direct requests and inquiries while reducing turnaround time for responses to 24 hours.

**Comprehensive Consumer-focused Web site:** In 2001 we became the only consumer-focused pain organization with a full-time Director of Educational Internet Services. In the past year, she doubled our content, increased the number of visitors to our site by 500%, and won a "Health on the Net Code of Conduct" Seal.

**No. 5: Raised Awareness about Patients' Needs with Allied Organizations**

In the past year, we met with and/or presented talks with over 50 health, medical and patient organizations from around the U.S. on the rights to pain care, how to find help and information, and the need to work together to do more.

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**Grant Request for 2002**

The American Pain Foundation requests an unrestricted educational grant from the Purdue Pharma Fund of \$250,000, in the form of a matching challenge grant, to support all of our patient-focused activities as follows:

**Free Patient Education Services**

- **Publications:** Expand the number of free publications we offer, including an additional major piece in Spanish, and support increased printing and distribution of them.
- **Email Info Service:** Support our ability to handle an increase in the number of inquiries and requests for information received via email.
- **Toll-free Info Service:** Support our handling a similarly higher number of toll-free calls.
- **Web Site:** Help us add more content and additional user-friendly features that our rapidly-expanding viewership needs.

**Public Awareness and Outreach**

- **Media and Outreach:** Help support our continued leading position as a source of information on pain for the media, a voice for people with pain, and a collaborator with health, medical, patient and community organizations.



- ***Pain Community News:*** Help us to continue publishing our newsletter and achieve our 2002 target of doubling our circulation.

#### **Regulatory and Legislative Advocacy**

Using unrestricted donations, we can continue fighting regulatory and policy changes that inhibit access to appropriate pain management by legitimate pain patients. But we will focus the bulk of our advocacy resources on taking the lead in building a coalition to develop and support comprehensive federal legislation to improve pain management. This is a multi-year effort, but our new Director of Government Affairs and I are committed to seeing this campaign through, because it has the potential to make a *major*, long-lasting difference in the lives of people with pain.

#### **Conclusion**

APF is already well underway in raising the resources necessary to increase our ability to serve and fight for people with pain in 2002. We hope we have earned your continued support.

Sincerely,

John D. Giglio, M.A., J.D.  
Executive Director

cc: Pamela Bennett  
Jeannette Doné



AMERICAN PAIN FOUNDATION®

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June 12, 2001

Mr. Robin Hogen  
Executive Director, Public Affairs  
Purdue Pharma, L.P.  
One Stamford Forum  
201 Tresser Boulevard  
Stamford, CT 06901-3431

Dear Robin:

Thank you again for giving us the opportunity to meet with you and Pam to present our *Stop Pain Now!* public awareness and grassroots outreach campaign plan. As promised, I've attached an updated Executive Summary and Budget for the campaign. I'm also including a selected portion of the *Community Action Kit* to give you a better idea of the specific materials and projects we will be distributing to those folks on the ground who will help organize the campaign in targeted markets.

All of us—the staff and Board of Directors—at the American Pain Foundation are deeply committed to this initiative and believe that it has the power to attract strong grassroots support and participation, and wide media attention. Now is precisely the right time to move accurate pain management information out to people in a planned, directed and aggressive way, and to motivate them to demand the care they need.

APF is also precisely the right organization to lead the initiative. We have firmly established ourselves as the leading independent, nonprofit information, education and advocacy organization serving exclusively the interests of people with pain. Moreover, we are the only consumer-focused organization that has a full complement of highly-experienced staff capable of making such an initiative a success. In addition to myself, staff members who will take a leadership role in our *Stop Pain Now!* campaign include:

- Lennie Duensing, Director of Communications and Outreach. Lennie developed the campaign concept and materials and will oversee the public awareness component. Lennie has over twenty years of experience developing and implementing public outreach campaigns. As Director of National Outreach for New York City's PBS station, WNET, she spearheaded outreach for *Before I Die: Medical Care And Personal Choices*, a Fred Friendly Seminars program, and for *Moyers On Addiction: Close To Home*. She also serves on the National Advisory Committee for Robert Wood Johnson's Community-

State Partnerships to Improve-End-of-Life Care, and was one of the authors of *A Guide to Public Engagement*.

- Eileen Meier, Director of Government Affairs, BSN, MPH, JD. Eileen was recently hired to head our legislative efforts. Eileen played an instrumental role in defeating the so-called "Pain Relief Promotion Act," and will lead *The Stop Pain Now!* Federal Pain Management Legislation component. Eileen has almost 20 years of professional experience as an oncology nurse, Senate staffer, health attorney and health lobbyist. Eileen also serves as a part-time instructor at Georgetown University on legal and policy issues in health care.
- Yvette Colón, MSW, ACSW, PhD (candidate), Director of Education and Internet Services. Yvette brings over 15 years of experience to the organization as a social worker and architect of the award winning Cancer Care website. Yvette will serve the campaign by developing a *Stop Pain Now!* section of the website, as well as providing content for educational materials.

Additionally, we have begun interviewing candidates for the full-time position of *Stop Pain Now!* Campaign Manager. Our goal is to find someone who understands the issues, has the ability to motivate others, and can manage the campaign details. In local areas, we will hire part-time coordinators where needed to ensure robust campaign activity and media coverage.

Finally, we have begun fundraising for *Stop Pain Now!* We have received \$100,000 to date and have several proposals outstanding. All of the funders we have met with have expressed genuine interest in the plan. Showing them that we have received a major investment from Purdue will help leverage funds from them.

Therefore, we are requesting an unrestricted grant of \$600,000/year for three years from Purdue to support the program, which we are estimating will cost \$1.59 million in the first year, and similarly-sized budgets in Years Two-Three for a total of \$4.77 million over three years.

We thank you, Pam, and Dr. Sackler for your strong interest in the campaign and your ongoing support of APF's efforts. It will truly take the work of all of us to Stop Pain Now! We look forward to your response.

Sincerely,



John D. Giglio, M.A., J.D.  
Executive Director

Atts.

cc: P. Bennett, L. Duensing



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## **STOP PAIN NOW!**

### ***A Public Awareness and Grassroots Outreach Campaign Bringing People Together to End the Pain Epidemic***

**Executive Summary**  
Submitted to Purdue Pharma, L.P.  
June 12, 2001

#### **Request**

The American Pain Foundation is requesting an unrestricted grant from Purdue Pharma of \$600,000/year for three years to support our *Stop Pain Now!* public awareness and grassroots outreach campaign, which we are estimating will cost \$1.59 million in the first year, and similarly-sized budgets in Years Two-Three for a total of \$4.77 million over three years.

#### **Overview of the *Stop Pain Now!* Campaign**

The American Pain Foundation (APF) is poised to launch an aggressive, three-year public awareness and grassroots outreach campaign called *Stop Pain Now!* The campaign is designed to publicize America's pain epidemic, provide pain sufferers with practical information, educate consumers about their rights to effective pain management, improve pain care, and make pain management a major healthcare priority. APF will partner with other leading health and advocacy organizations to undertake this first-ever coordinated, consumer-based campaign built on three major components that industry is not well-situated to implement. **The ultimate goal of *Stop Pain Now!* is to increase the number of Americans who receive effective pain relief.**

#### **The Problem**

Over 50 million Americans suffer from chronic pain, and each year another 25 million experience acute pain. Although nearly all pain can be relieved or eased, most goes untreated, undertreated, or improperly treated. In spite of this fact:

- Healthcare professionals, policy makers, and the general public do not consider pain a critical health issue.
- Most consumers remain unaware that pain can be relieved or controlled and that they have the right to effective pain management.

- Healthcare professionals are not adequately trained to manage pain effectively.
- Both consumers and healthcare providers mistakenly believe that opioid medications are addictive.
- Pain care gets scant attention in most major health care organizations and research institutions.

### **An Outstanding Opportunity—The Time Is Right**

The pain epidemic needs urgent action, and a number of developments have converged to make this the ideal time to launch the *Stop Pain Now!* Campaign.

- ☐ APF has firmly established itself as the leading independent, nonprofit information, education and advocacy organization serving exclusively the interests of people with pain.
- ☐ The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) recently established new pain management standards. They provide a window of opportunity to organize and launch pain awareness initiatives, from the local to the national level, that focus attention on the problem of pain, encourage healthcare professionals and facilities to provide better pain care, and inform consumers about their rights to effective pain care.
- ☐ The media is becoming increasingly interested in pain management. This has been fueled by the new JCAHO standards, the growing attention to end-of-life care, concerns about physician-assisted suicide, and - most recently - sensationalized stories of opioid diversion and abuse.
- ☐ The vocal and affluent “Baby Boomers,” who are a key target audience for us, are finding their parents or themselves with pain.
- ☐ Congress recently completed a bruising debate on legislation that would have inhibited the legitimate use of controlled substances, and it is now open to considering proactive ideas for legislation that will truly improve pain care.

### **The Three Major Campaign Components**

The *Stop Pain Now!* Campaign consists of three distinct, yet interrelated components.

- 1) *Stop Pain Now!* Public Awareness and Grassroots Outreach Campaign
- 2) Proactive Federal Pain Management Legislation
- 3) Pain Management Measures for HMOs

## **Component 1: *Stop Pain Now!* Public Awareness and Grassroots Outreach Campaign**

The single largest component is a public awareness and grassroots outreach campaign. APF will lead and launch a state-by-state initiative to increase the visibility of the pain epidemic, educate the media and consumers, raise pain "literacy" and hopefully increase demand for better pain management. The campaign will consist of a variety of outreach activities that will be implemented by volunteers (and part-time paid staff where needed) that APF helps recruit and guide in cooperation with local affiliates of key national organizations, particularly the American Alliance of Cancer Pain Initiatives (AACPI), the American Society of Pain Management Nurses (ASPMN), and the American Chronic Pain Association (ACPA).

APF will bring to the effort its expertise in communications and outreach, content and materials development, management and leadership experience, and public relations strategies and tactics. Our partners will provide the local leadership and infrastructure. AACPI, which has agreed to participate as a collaborating organization, has initiatives in half of the states in the U.S. AACPI and APF have already identified states with strong leadership, energized memberships, and track records of implementing successful projects. APF has also supplemented that network by developing strong relationships with the leadership of selected chapters of ASPMN and ACPA who are ready and eager to lead the campaign in their areas.

### **a) *Stop Pain Now!* to Be Piloted in Five Markets**

After evaluating the on-the-ground strengths of our partners, our ability to penetrate specific media markets, our relevant capacities, and the need for pain awareness in specific geographic regions, we have chosen five markets to pilot the project in Year One: Maryland, Delaware, Virginia (central and southern), Florida (northern), and Utah. APF has already begun discussions with leaders in each of these areas.

In addition to the five selected markets where our efforts and resources will be concentrated, APF will also provide free copies of our comprehensive *Community Action Kit* (described below), patient education materials (e.g. *Pain Action Guides*, *Bill of Rights Cards* and *Posters*, etc.), and some limited, basic technical assistance to other groups who are interested in conducting a public awareness campaign. The *Community Action Kit* is designed such that small, local efforts (e.g. by a single healthcare institution) as well as larger coalitions can pick and choose among the many projects outlined in the kit that best fit their needs. APF will also carefully track and document activities in these areas. Results will be incorporated in the evaluation process after the first year.

If all goes as planned, we will expand the number of targeted states to up to ten in Year Two, and up to 15 in Year Three.

### **b) Pre-launch Preparation Almost Complete**

In preparation for launching the public awareness/grassroots outreach campaign in each state APF has completed the following:

- ❑ **Community Action Kit:** We have developed a comprehensive, step-by-step *Stop Pain Now! Community Action Kit* (selected portions attached) which include:

- Background Information
- Identification of Opportunities, Campaign Goals and Key Messages
- Blueprint for Organizing the Community/Coalition Building
- A Menu of Action Ideas
- *Making Pain News!* Media Guide (sample releases, fact sheets, etc.)
- Resources List (that can be tailored to local needs)
- Pain Facts, and
- Tools to Implement the Action Ideas

- ❑ **Educational Materials:** We have created basic materials for distribution including our *Pain Action Guide* and *Pain Care Bill of Rights Card* and *Poster*. Produced prior to campaign because of high demand, these publications are being distributed to hospitals, nursing homes, pain clinics, and physicians' offices throughout the nation. The "best selling" *Pain Action Guide* is about to go into its third printing, and numerous healthcare institutions and organizations have been given permission to reprint them in-house in large quantities. Feedback on all of our materials has been consistently positive.
- ❑ **Partnerships:** We have developed good working relationships with key people at the American Alliance of Cancer Pain Initiatives, the American Society of Pain Management Nurses, the American Chronic Pain Association, and numerous local pain leaders in our target states.
- ❑ **Full-time Campaign Manager:** We have begun a search for a full-time *Stop Pain Now!* Coordinator who will act as a leader/liaison with local groups, provide community organizing training, on-going technical assistance, resources and support. Once this position is filled, APF will identify and hire part-time local coordinators as needed.

Other pre-launch elements close to completion include creating a look and logo for the campaign, and publishing and distributing the *Community Action Kit*.

**c) Major Planned Activities for the *Stop Pain Now!* Campaign**

Once *Stop Pain Now!* is underway, major activities that we will seek to complete in each participating state include:

- ❑ **Training:** We will convene a training conference in their area, or one in Baltimore for all target states, to train local leaders on the purpose and overall goals of the campaign, current information about pain and pain management issues, and practical ways to implement the campaign in their areas. Led by a trained facilitator, the training will include presentations by leaders in pain management; a workshop in utilizing the media; and sessions on community organizing, local fundraising, and evaluation.

- ❑ **Initial Pain Survey:** We will conduct a "pain survey" in each of the areas to determine public awareness of the pain problem and attitudes about pain and pain treatment options. Findings from the first survey will be compared to findings from surveys that will be conducted in three to four years to determine the success of the initiative. The initial surveys will also serve to launch the campaigns and provide news "hooks" for stories about our issue.
- ❑ **Wide Materials Dissemination:** Our local partners will widely distribute the *Pain Care Bill of Rights Card and Poster*, the *Pain Action Guide*, and other materials to hospitals, nursing homes, doctors' offices and other healthcare facilities. Coordinators in local areas will work with coalition members to identify healthcare facilities, track the number of pieces distributed, and collect feedback.
- ❑ **Consumer Workshop:** We will help facilitate the teaching of consumers about their right to effective pain management. An hour-long workshop, based on the information in the *Pain Action Guide*, will be held in at least one local venue (e.g. community center, church, library), and more where able.
- ❑ **Pain Awareness Month:** We will help our partners work to establish a *Pain Awareness Month* in their state or on a local level to attract media attention to the issue and provide an opportunity for groups to conduct activities throughout their communities.
- ❑ **Media Relations:** Finally, we will assist our partners in aggressively promoting all aspects of the campaign to local and national media.

**d) Major Optional Activities for Each State to Choose From**

Examples of other activities outlined in our *Community Action Kit* which states may chose to implement, depending upon their resources, interest, etc., include:

- **Health Professional Training:** Training healthcare professionals and consumers to do "pain screenings" through an hour-long slide presentation.
- **Town Hall Meeting:** Hold a Town Hall Meeting focusing on the value of opioids in the treatment of pain, and potential abuses. Community members will work together to ensure that pain sufferers have access to effective pain care, while at the same time, working to prevent diversion and abuse.
- **Additional Consumer Workshops:** Conduct additional consumer workshops as described above.

**e) On-going Media Outreach—A Key Campaign Element**

All activities will be designed with a media focus. In addition to "making news" through media-specific activities such as local surveys and *Pain Awareness Month*, APF will work closely with coordinators to identify other opportunities to generate news and feature stories about pain



management and the campaign. Where needed, local *Stop Pain Now!* leaders will be trained by APF on effective ways to reach and use the media. A comprehensive "Making Pain News" section is also included in the *Community Action Guide* that provides detailed how-to media information and sample media materials (e.g. releases, alerts, backgrounders, fact sheets, etc.).

## **Component 2: Proactive Federal Pain Management Legislation**

APF will continue to lead and expand a national coalition of organizations and individuals to work for passage of proactive federal legislation that improves and promotes pain management in a variety of ways. Such legislation would likely include:

- ☐ **Professional Education and Training.** Provide incentives for medical, chiropractic, nursing, social work, physical and rehabilitative medicine, and related schools that receive federal funding to provide comprehensive education and training in pain management.
- ☐ **Medicare and Medicaid Coverage.** Require Medicare and Medicaid to cover pain prevention and treatment services and medications—including removing the Medicare restriction that denies coverage for all self-administered pain medications and other pain treatment services currently not reimbursed.
- ☐ **Public Awareness Campaign.** Fund a multi-million dollar, multi-year, nationwide public awareness campaign including mass media along the lines of successful federal campaigns raising awareness of cancer, AIDS prevention, and high blood pressure.
- ☐ **Underserved Populations.** Require all healthcare organizations and providers receiving federal funding or reimbursement to show they adequately assess and manage pain in all underserved populations, including minorities, the young, the elderly and women.
- ☐ **Reduce Federal Regulatory Barriers.** Work to eliminate unnecessary federal policies that inhibit the appropriate use of valuable pain medications and services.
- ☐ **Basic and Clinical Research and Outcomes-based Guidelines.** Increase federal funding for basic and clinical research on pain. Also fund outcomes-based guidelines on treating different kinds of chronic and acute pain and delivering pain management services.

Through the coalition and network of activists APF created last year, our website, and contacts developed through the grassroots public awareness campaign, APF will mobilize people with an interest in pain issues to begin the process of developing consensus for such a proposal, then building support for it. As with previous efforts, APF will strategically incorporate media outreach into this legislative campaign.

Like the other campaign components, this is going to be at least a three year effort, and will be quite a challenge. But given our track record, APF has shown that it is the pain-related organization best situated and staffed to lead such an ambitious campaign

### **Component 3: Pain Management Measures for HMOs**

APF will work with several of the nation's top pain experts, some of whom have already begun discussions with us, to establish pain management measures for HMOs analogous to those JCAHO recently issued for hospitals and other healthcare facilities. In the first year, APF will develop a working relationship with the leadership of the National Committee for Quality Assurance, and create an advisory committee of key leaders to collaborate on the parameters of these measures. In the second year, APF and others will work with NCQA on developing pain measures. The American Alliance of Cancer Pain Initiatives has already expressed strong interest in working with APF on this project. In the third year, APF will work to ensure NCQA adopts pain measures and develops a plan for implementation. APF will then generate significant media coverage of the adoption of the new measures.

### **Conclusion**

APF is confident that this campaign has the right combination of elements and spirit to help change the way that the public, healthcare professionals, the media, and policy makers perceive and respond to pain management issues. It also provides for flexibility to allow local leaders and participants to tailor their role in a way most appropriate for them. The constituency and desire to help affect change has long been out there in the pain community. What those constituents have lacked is an organization that can provide leadership, expert staffing, resources and a specific game plan to implement. With your support, the American Pain Foundation can provide all of this to many individuals and organizations at the grassroots level who are eager to join us in taking action to ***Stop Pain Now!***

## **STOP PAIN NOW!**

### **CAMPAIGN BUDGET OVERVIEW FOR YEAR ONE**

***Component One: Public Awareness/Grassroots Outreach Campaign*** \$1,207,500

***Component Two: Proactive Federal Legislation*** \$240,120

***Component Three: Pain Performance Measures for HMOs*** ~~\$142,520~~

**TOTAL** \$1,590,140

**STOP PAIN NOW! Campaign Budget**

**Component One: Public Awareness/Grassroots Outreach Campaign**

**Salaries**

Executive Director @ 10%	
Campaign Director @80%	
Pain Mgmt. Advisor @ 10%	
Communications Director @ 50%	
3 State Grassroots Coordinators @ 50%	
Administrative Assistant @ 50%	
	<b>\$ 185,000</b>

<b>Payroll Taxes and Benefits</b>	<b>\$ 55,500</b>
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**Campaign Outreach and Materials**

Bill of Rights Pocketcard (350,000 printed @ \$.50 each)	\$ 175,000	
Pain Action Guide (150,000 copies @ \$.68 each)	\$ 102,000	
Poster/Bill of Rights (100,000 @ \$1.00 each)	\$ 100,000	
Local Action Kits (500 @ \$15.00 each)	\$ 7,500	
Slide Presentations for Campaign (50 @ \$25)	\$ 1,250	
		<b>\$ 385,750</b>

**Media Outreach**

Branding/Public Relations		
Message Development, Logo, Consulting	\$	20,000
Campaign Launch		
Pain Literacy Surveys in 5 Target States	\$	95,000
Media Kits (release, backgrounders, fact sheets, etc.)	\$	10,000
Media Outreach	\$	56,000
in 5 targeted markets; print, broadcast, on-line etc.)		
Media Monitoring	\$	4,000
		\$ 185,000

<b>SPN Component of Website</b>	<b>\$ 20,000</b>
Design, Database, Network, Hosting, Promotion	

<b>Conference and Trainings</b>	<b>\$ 55,000</b>
Hotel, Travel, AV, Food, Information Packets	

<b>SPN Staff Travel</b>	<b>\$ 25,000</b>
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<b>Postage</b>	<b>\$ 75,000</b>
150,000 pieces @ average of \$.50	

<b>Phone/Fax/Copying</b>	<b>\$ 20,000</b>
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<b>Overhead (Space, Equipment, Admin)</b>	<b>\$ 201,250</b>
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<b>TOTAL</b>	<b>\$ 1,207,500</b>
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**STOP PAIN NOW! Campaign Budget**  
***Component Two: Proactive Federal Legislation***

**Salaries**

Executive Director @ 20%  
Campaign Director @ 20%  
Government Relations Director @ 80%  
Communications Director @ 15%  
Administrative Assistant @ 10%

\$ 112,000

Payroll Taxes and Benefits

\$ 33,600

Media Outreach

\$ 25,000

Website

\$ 15,000

Meetings for Coalition and Experts

\$ 7,500

Travel

\$ 5,000

Phone/Fax/Copying

\$ 2,000

Overhead (Space, Equipment, Admin)

\$ 40,020

**TOTAL** \$ 240,120

**STOP PAIN NOW! Campaign Budget**  
***Component Three: Pain Performance Measures for HMOs***

**Salaries**

Executive Director @ 10%  
Government Relations Director @ 20%  
Communications Director @ 10%  
Administrative Assistant @ 10%

\$ 37,000

Payroll Taxes and Benefits

\$ 11,100

Media Outreach

\$ 15,000

Website

\$ 5,000

Meetings

\$ 5,000

Travel

\$ 2,000

Phone/Fax/Copying

\$ 2,000

Overhead (Space, Equipment, Admin)

\$ 15,420

Policy Consultant

\$ 50,000

**TOTAL** \$ 142,520

## Barbara Friedman

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**From:** John Giglio [jgiglio@painfoundation.org]  
**Sent:** Tuesday, June 12, 2001 10:32 AM  
**To:** Nina Link (E-mail)  
**Cc:** Barb Friedman (E-mail)  
**Subject:** Grants Receivable

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

Nina - On the May YTD statements we had Purdue Pharma as having \$150,000 in grants receivable. My notes indicate they only have \$125,000 in receivables. Can you tell me where you got the 150 number from?

John

John D. Giglio, M.A., J.D.  
Executive Director  
American Pain Foundation  
111 S. Calvert St. - Suite 2700  
Baltimore, MD 21202  
Ph: 410-385-5251  
Fax: 410-385-1832

APF - The Nonprofit Voice for All People Affected by Pain:  
Information, Education & Advocacy



1 5,193,883; 6,707,083. Das. 354,308. Pressure Seal 4,918,128, 5,253,796, and other parts. - 0221

PAYOR		VENDOR NO.	VENDOR NAME		CHECK NO.
Purdue Pharma L.P.		17148	AMERICAN PAIN FOUNDA		76457
INVOICE DATE	INVOICE NO.	DESCRIPTION		DISCOUNT	NET AMOUNT
25-JUL-01	25-JUL-01	SAYLES 2ND INSTALL-MILBANK FO		0.00	125,000.00
TOTALS					125,000.00

REMITTANCE ADVICE

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**Purdue Pharma L.P.**  
One Stamford Forum  
Stamford, CT 06901-3431

Chase Manhattan Bank Delaware  
Wilmington, DE 19801-1167  
4910-09

CHECK NO. 76457 62-26  
62-26  
62-26

DATE 17 AUG 01  
PAY TO THE ORDER OF  
AMERICAN PAIN FOUNDATION  
111 SOUTH CALVERT ST  
STE 2700  
BALTIMORE MD 21202

One hundred twenty five thousand and 00/100 Dollars

*Diana C. Cichowski*  
*Ronald D. Levine*  
AUTHORIZED SIGNATURE

VOID 90 DAYS FROM DATE ISSUED

076457 031100267 6301449108 509

Purdue ID # 574  
Lynn ID # 499





AMERICAN PAIN FOUNDATION<sup>SM</sup>

American Pain Foundation, Inc.  
111 South Calvert Street, Suite 2700  
Baltimore, MD 21202  
Phone (410) 385-5276  
Fax (410) 385-1832  
[www.painfoundation.org](http://www.painfoundation.org)

August 22, 2001

Macy Vajdel  
TD WATERHOUSE INVESTOR SERVICES, INC.  
36 South Charles Street, Suite 1920  
Baltimore, MD 21201

**Re: Check #76457 – Purdue Pharma L.P.**

Dear Macy:

Please deposit the enclosed check in the amount of \$125,000 into our TD Waterhouse Account, Acct. #3743365110.

Thank you.

Bonnie Weissfeld

cc: John D. Giglio, J.D.  
Nina Link

Enclosure

**PURDUE PHARMA FUN**

One Stamford Forum  
Stamford, CT 06901-3431  
(203) 588 8456 • Fax (203) 588 6223  
www.purduepharma.com

March 30, 2004

4/14/04  
Drafted reply & thank  
you for Will's  
signature.

Mr. Will Rowe  
Executive Director  
American Pain Foundation  
201 North Charles Street  
Suite 710  
Baltimore, MD 21201

Dear Will,


On behalf of Purdue Pharma L. P. and its associated companies, we are pleased to enclose a check from the Purdue Pharma Fund in the amount of **\$125,000 which represents the first installment of our 2004 matching contribution unrestricted educational grant for 2004** to the American Pain Foundation.

This grant is to support the APF in its education and advocacy efforts to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research and advocating to remove barriers and to increase access to appropriate and effective pain management.

As usual, we appreciate your updating us quarterly as to the results of your work. We share the progress of your efforts with our colleagues.

Best wishes for continued success in your development efforts on behalf of the American Pain Foundation.

Best regards,


  
Pamela Bennett, BSN, RN  
Senior Director, Advocacy

Enclosure – Check No. 100465 (CR 23-04)

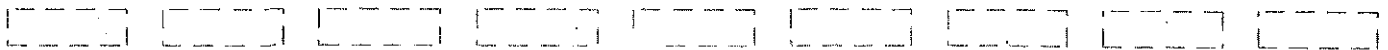
cc:	R. Hogen	A. Must
	J. DaBronzo	M. Stanton
	J. Heins	J. Doné-Lagemann
	R. Novak-Tibbitt	

PAYOR Purdue Pharma Fund		VENDOR NO. 1004075	VENDOR NAME AMERICAN PAIN FOUNDATION		CHECK NO. 100465
PAYMENT METHOD SUPPLEMENT LD Return to J. DONE-LAGEMANN					
INVOICE DATE 03/04/2004	INVOICE NO. 2304	DESCRIPTION NO.23-04, CHALLENGE GRANT  2321/2752 - Matching Gfr	DISCOUNT 0.00	NET AMOUNT 125,000.00	SAP DOC. NO. 1900003962
TOTALS				\$ 125,000.00	

REMOVE DOCUMENT ALONG THIS PERFORATION

MOORE SECURITY MARK™ • MOORE SECURITY MARK™ • MOORE SECURITY	Purdue Pharma L.P. D/B/A Purdue Pharma Fund One Stamford Forum Stamford CT 06901-3431		JPMorgan Chase Bank 1411 Broadway New York NY 10018		CHECK NO. 100465 1-2 210
	DATE 03/19/2004		PAY THIS AMOUNT ONLY		
	PAY ONE HUNDRED TWENTY-FIVE THOUSAND Dollars ***		125,000.00		
	VOID 90 DAYS FROM DATE ISSUED				
PAY TO THE ORDER OF		AMERICAN PAIN FOUNDATION 201 NORTH CHARLES STREET STE 710 BALTIMORE MD 21201-4111			
		 AUTHORIZED SIGNATURE			

⑈ 100465⑈ ⑆021000021⑆ 020835647⑈





Purdue ED # 574  
Mft ED # 565

**Purdue Pharma L.P.**

One Stamford Forum  
Stamford, CT 06901-3431  
(203) 588 8000  
Fax (203) 588 8850  
[www.purduepharma.com](http://www.purduepharma.com)

January 4, 2002

Ms Yvette Colón, MSW, ACSW, BCD  
Director of Education & Internet Services  
American Pain Foundation  
201 N Charles Street  
Suite 710  
Baltimore, MD 21201

Dear Yvette,

On behalf of Purdue Pharma L. P. and its associated companies, I am pleased to enclose a check from The Purdue Pharma Fund in the amount of \$25,000 for the new American Pain Foundation online pain discussion program.

The Purdue Pharma Fund is a new community outreach program that Purdue has developed to strategically align our investments in nonprofit organizations that share our business interests.

Best wishes for a successful launch of the online pain program.

Sincerely,

Robin Hogen  
Executive Director, Public Affairs

Enclosure – Check No. 084888

cc: Pamela P. Bennett, BSN, RN  
Jeannette Doné

1/15/02  
Shirley will write to  
confirm receipt of grant.

PAYOR		VENDOR NO.	VENDOR NAME		CHECK NO.
Purdue Pharma L.P.		17148	AMERICAN PAIN FOUNDA		84888
INVOICE DATE	INVOICE NO.	DESCRIPTION	DISCOUNT	NET AMOUNT	
20-DEC-01	MCINT12200	:DONE-LAGEMANN J: MESSAGE BOARD	0.00	25,000.00	
		Online Group Program			
TOTALS				25,000.00	

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Purdue Pharma L.P. *574/565* Chase Manhattan Bank Delaware  
 One Stamford Forum  
 Stamford, CT 06901-3431  
 DATE 31-DEC-01  
 PAY: Twenty five thousand and 00/100 Dollars\*\*\*  
 PAY TO THE ORDER OF AMERICAN PAIN FOUNDATION  
 201 NORTH CHARLES STREET  
 SUITE 710  
 BALTIMORE, MD 21202

CHECK NO. 84888 62-26  
 PAY THIS AMOUNT ONLY  
 \$25,000.00  
 VOID 90 DAYS FROM DATE ISSUED

*Edmund B. M...*  
 AUTHORIZED SIGNATURE

⑈084888⑈ ⑆031100267⑆ 6301449108 509⑈



bcc Bash - Purdue 12512

**American Pain Foundation**

201 N. Charles Street, Suite 710

Baltimore, MD 21201

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

1/16

Dear Robin -

On behalf of APF, David Hamborne and other professionals committed to providing a new Online Support Group to replace the now-closed ~~APF~~ AOL Pain Relief Center, I want to thank you, Pam and the Purdue Pharma Fund for providing us with a \$25,000 grant to launch this project. APF will be investing some of its own resources to match Purdue's grant, so that we can implement this project right.

Thanks again, Robin, for Purdue's continued & strong belief in the future of the American Pain Foundation.

Warmly,  
John



**American Pain Foundation**

201 N. Charles Street, Suite 710

Baltimore, MD 21201

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

1/16

Dear Pam -

Well, what can I say? Your quick action in looking us up w/ Dave Hamborne and moving our proposal through for an on-line support group just blew us away. Needless to say, Yvette and David are psyched, because they so wanted to do this.

And it also helps APF as an institution by raising our visibility and showing how we continue to grow.

Pam, thank you for your continued full commitment to an organization that you helped build, and that will always be a part of who you are as a professional.

Warmly,  
John