



AMERICAN PAIN FOUNDATION®

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September 19, 2002

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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)
- ⇒ **Email Info Service:** Pain sufferers can get answers to specific questions submitted via email (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 1st 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.

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 Thernstrom 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.)

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*. 90
- 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:

- | | |
|----------------------|---|
| <i>Issue Area 1:</i> | Conduct a National Public Awareness Campaign on Pain Management and How to Get Help |
| <i>Issue Area 2:</i> | Provide Federal Support for Professional Training in Pain Management |
| <i>Issue Area 3:</i> | Reduce Regulatory Barriers to Pain Management |
| <i>Issue Area 4:</i> | Increase Federal Support for Pain Management Research |
| <i>Issue Area 5:</i> | Expand Federal Reimbursement for Pain Care Treatments and Services |
| <i>Issue Area 6:</i> | 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