

National Initiative for Glaucoma Control, Inc.

1140 Connecticut Avenue, N.W., Suite 606, Washington, D.C. 20036 • (202) 466-4555
Executive Director, Mike Gorman • Associate Director, Pamela A. Nash

March 19, 1984

TO : Tony

FROM: Pamela *pan*

RE : National Initiative for Glaucoma Control, Inc.

Attached are a number of documents which outline some of our thinking and planning to date.

The package contains:

- o Attachment A - a Gorman memo entitled "Planning for Glaucoma Initiative".
- o Attachment B - a draft letter to Reinecke and Lichter asking them to sign the solicitation letter to potential sponsors.
- o Attachment C - the solicitation letter to potential sponsors.
- o Attachment D - a proposal for the Initiative's letterhead.
- o Attachment E - a memo from Mike with his thoughts on the letterhead.
- o Attachment F - a draft questionnaire or survey which will be sent to all state and selected city/county health officials.

If you will read through the pile you, Mike, Jerry and I can discuss the Initiative's activities at our March 28 summit meeting next Wednesday. We will expect you in the Initiative's headquarters at 1140 Connecticut Avenue, N.W., Suite 606 at about 12:30 P.M.

Looking forward to seeing you then.

PAN/eak

bcc: *Mike Gorman*

From: Mike Gorman

Planning for Glaucoma Initiative:

1. Obviously the first problem is the announcement of our new Initiative. There are a number of ways to do this depending upon how much manpower we have and what funds are available. In this case, since we are a quite small operation at the present time, we have to develop a realistic, cost-effective plan.
2. The John Doe letter is, of course, one way in which we can introduce ourselves. However this letter will be initially used to pick up sponsors. Its further use as an educational tool will depend upon the dramatic quality of the letter.
3. The standard method of introduction is, of course, a fairly high powered press conference. First of all, it requires one or two prominent spokespersons. We are handicapped in this area. Let us say that one of the presenters is an eye doctor. Whom do we have as Initiative officers? We just have Dr. Paul Lichter and Dr. Robert Reinecke. We don't really have a genuine "biggie" in the eye care field comparable to a Michael De Bakey in the heart field. Neither Mary Lasker nor Claude Pepper can, for a number of obvious reasons, carry off this assignment.

Naturally, you have to determine whom you want to reach. If you want to go really big and create a total atmosphere and acceptance for significant expansion of the glaucoma field, you really need to contract with a public relations outfit which has good medical and press lists and several good staffers for the conference. This kind of an endeavor is expensive. For example, our press room at the 1977 National High Blood Pressure conference in L.A. really put high blood pressure on the map. However, a very competent New York public relations outfit was used and they started work several months before the conference began. The cost of the contract alone was \$28,000, with many additional costs absorbed by the National Heart Institute.

4. Jerry Wilson, Pam and I have been discussing some of these questions over the past few days. Certain things were apparent to us. First of all, we really have no allies in the eye care field. The American Academy of Ophthalmology, the National Society to Prevent Blindness, Research to Prevent Blindness - all of these take a rather dim view of what we are doing. This leads us to the conclusion that we have to build slowly and carefully and carve out a distinctive goal which none of the aforementioned outfits is involved in.

I don't think in the very beginning we can announce that our sole goal is the passage of federal legislation which will provide project grant monies to the states for the screening and referral of glaucoma patients. You have to build up what Mary Lasker calls an "atmosphere for legislation". In other words, you will have to have enough people caring enough to contact their congressmen on this issue. You also have to make sure that yours is a

targeted and visible approach. In light of the fact that there is a National Eye Care Project currently in being which has received the blessing of the President makes the task much more difficult.

5. Timing - It is obviously impossible to bring off any hearings on glaucoma legislation in this, a presidential year. As to 1985, all is speculation. There are obvious obstacles. To give you an example; in talking to my good friend, the State Health Commissioner of New York state, he expressed a good deal of interest in eye care but wanted to know why I couldn't package a total eye care project grant. This he could conceive of being sold to a legislator, but just singling out glaucoma created skepticism in his mind. As he said to me: "Mike, won't any legislator bring up the point of why you are not covering any other eye diseases?"
6. Follow-Up Info on our activities to various constituencies -
Letters to:
State Health Depts. - City Health Depts. - County Health Depts.
Letter tailored to getting them to give glaucoma high priority-
Questionnaire technique - What are they now doing -
7. Separate Letter to Governors in connection with recruiting them as sponsors - What are they doing in glaucoma?
8. Finally, approval of John Doe letter by whom? Just the Co-chairmen?
9. Two model state legislative efforts whereby Jerry will attempt to get legislative action. Possibilities appear to be Florida and Georgia because of a prior program emphasis.

DRAFT

Dear Dr. Lichter
Dear Dr. Reinecke

The National Initiative for Glaucoma Control, Inc. is about to start its formal campaign to enlist sponsors whose names will be listed on the Initiative's letterhead.

The invitations will seek approximately 70 sponsors among whom will be leaders in ophthalmology, other medicine and health areas, Governors, legislators and officials and luminaries in a variety of fields.

Mrs. Mary Lasker and Congressman Claude Pepper, co-signors of the letter (copy enclosed), are eager to get this invitation out but feel strongly, as I do, that the addition of your name, a most prestigious and respected name in ophthalmology, would help express the broad range of support that is fundamental to the Initiative's objectives.

While this letter will seek a broad range of sponsors, several sponsors are already on board by virtue of their awareness of the Initiative through personal contacts. They include: The Honorable Paul Rogers, The Honorable Henry Waxman, David Epstein, M.D., Thomas Hutchinson, M.D., Herbert Kaufman, M.D., Robert Ritch, M.D., Bernard Schwartz, M.D. and George Spaeth, M.D.

Won't you let me know right away if you will be a co-signor of this invitation letter? We would be honored.

Please call me at 202-296-4435.

Sincerely,

Mike Gorman
Executive Director

MG/eak

Enclosure

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Executive Director, Mike Gorman • Associate Director, Pamela A. Nash

Dear John Doe:

This is an urgent appeal for you to join forces with us in an all out effort to reduce the ravages of glaucoma, an eye disease caused by excessive fluid pressure within the eye.

Glaucoma is the leading cause of blindness in the United States today. In a recent Gallup poll, blindness ran second to cancer as the affliction most feared by the American people. We have no absolutely precise idea of its extent. For a number of years organizations in the eye care field have been using a figure of two million glaucoma victims - one million who know that they have it, and another million who don't.

This two million figure has come into question in recent studies. For example, the American Academy of Ophthalmology in a 1983 survey of laser surgery for glaucoma, estimated that from five to six million individuals suffer from some form of glaucoma, with the percentage of the population with glaucoma increasing sharply as people grow older. In addition, according to the 1983 report of the Glaucoma Panel of the National Eye Institute, as many as 10 million people may have elevated intraocular pressure, called "ocular hypertension"; an undetermined percentage of these people will eventually develop glaucoma.

We are concentrating on glaucoma because it is a field which offers enormous hope if detected and treated in its earliest stages. Without this early detection and subsequent treatment, the victims of the disease will eventually go blind. Unlike practically all other eye diseases, glaucoma is an irreversible sentence to blindness. As long ago as 1975, a group of distinguished ophthalmologists appeared before a congressional committee to plead for a national program of early screening and follow-up treatment, warning that "within the scope of our present knowledge, those who have lost any part of their sight through glaucoma will not regain it."

We are also moving into this field because of its enormous challenges in practically every walk of American life. For example, glaucoma ranks behind only heart disease and arthritis in its impact upon our elderly population. The number of people over age 35 in America will grow from ninety-six million in 1980 to one hundred and thirty-five million in just fifteen years from now. Beyond thirty-five years of age, glaucoma begins its steep rise in incidence, up to its devastating impact among those over sixty-five years of age. In addition to the threat of blindness among the elderly, it incapacitates many millions more in terms of low, partial vision among this same elderly group. It is estimated that twelve million people in the United States suffer some degree of visual impairment.

According to the National Eye Institute, the deciding factors in preventing blindness from this often symptom-less disease are early detection, appropriate intervention through drugs and other therapies and long-term follow-up. Over the past decade or more there have been some successful screening efforts, but they have never been able to reach more than one hundred and fifty thousand people a year. We understand the reasons for this; the professional and lay organizations in the eye care field cover an increasingly wide spectrum of eye diseases to which their attention must be directed, so that they can not single out one eye disease for total emphasis.

However, we see the necessity and urgency of a targeted, long overdue effort solely devoted to glaucoma. That is why, after several years of planning, we have formed the National Initiative for Glaucoma Control. We believe it will serve as the focal point for a broad-based glaucoma detection and control program working in close cooperation with existing professional and lay national organizations in the health care field, and with the National Eye Institute. As an example, we know that diabetes is the major cause of new cases of blindness in the United States; we propose to work with leaders in the field of diabetes to reverse this trend.

The Glaucoma Initiative is modeled after a similar effort in the cardiovascular field which concentrated on high blood pressure. When we started our High Blood Pressure Initiative in 1972, millions of Americans were unaware that they had high blood pressure and how serious this was. Through relentless educational efforts and the support of thousands of volunteers, we succeeded in making high blood pressure a major national health issue and, in so doing, created a program which led to truly dramatic reductions in the incidence of high blood pressure-related deaths from stroke and heart disease. As a result of our educational efforts, the Congress provided funds in a project grant program to the States directed to the establishment of high blood pressure detection and follow-up programs. In very simple terms, we made the once mysterious high blood pressure a household word. In all of this, it was the voluntary effort which provided the major push; the federal and state monies provided less than one half of the funds for this enormous national effort, but these public funds were a necessary catalyst. We therefore envisage comparable federal grants to the states in the field of glaucoma.

Won't you join us in this exciting challenge by becoming a sponsor of this long overdue effort? There are no dues or membership fees. From time to time we would like to call upon you for advice and counsel. Since we are eager to get off the mark within the next month, won't you send your acceptance today to:

Mike Gorman, Executive Director
National Initiative for Glaucoma Control
1140 Connecticut Avenue, N.W., Suite 606
Washington, D.C. 20036

Mary Lasker, Co-Chairman
President, Albert and Mary Lasker
Foundation

Rep. Claude Pepper, Co-Chairman
House of Representatives
United States Congress