

Association of Birth Defect Children Inc.

Dr. C. Everett Koop
Surgeon-General
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Humphrey Bldg.
200 Independence Ave, SW
Washington, DC 20201

December 20, 1982

Dear Dr. Koop,

In November of last year, I had the pleasure of meeting with you, Ralph Hill and Susan McFalls to discuss our concerns about Bendectin. At that time, I also told you about our parents group which represented hundreds of families whose children's birth defects were associated with Bendectin use during pregnancy.

Our organization has recently changed our name to the Association of Birth Defect Children, Inc. Our new group is a nonprofit organization established to provide information and support to families of children with birth defects believed to be caused by the mother's exposure to drugs, chemicals, radiation and other environmental agents. ABDC disseminates information through a quarterly newsletter and inquiry response service geared primarily to parents, educators and professionals in the medical and health related fields.

Our newsletter currently goes out to over 700 members in the United States and Canada, a comparable group of 450 members in England, a group of 175 in Australia, a group of 500 in Japan and families in Italy, Ireland, Germany & Switzerland. We have received requests for our materials from families of children with birth defects, nurses, doctors, midwives, child-birth educators, schools, hospitals and consumer groups. We have recently started getting requests from a number of public libraries.

The Association of Bendectin Children began nearly 3 years ago. We have existed entirely on donations from our members. Some months we didn't know whether we could continue or not, because many parents in our group cannot contribute anything since they are already overwhelmed by the costs of medical care for their children.

Now that we have been approved for nonprofit status, we are hoping to be able to find some outside help with funding. I have already looked through the Catalog of Federal Domestic Assistance and spent hours phoning programs that might fund organizations like ours. However, as you know,

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budget cuts have drastically limited the federal funds available for any projects like ours. After the first of the year, we will begin to look at the availability of funds from private foundations.

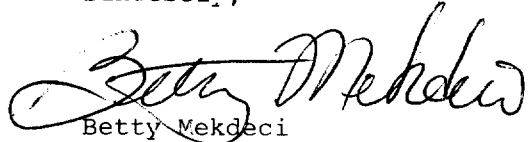
Many families in our group have now had more children. Since their experience with Bendectin, they have been extremely cautious in subsequent pregnancies and all the babies have been born beautifully normal. We feel that if our group can prevent the birth of a single defective baby, we have performed a valuable service to our country and its families. We also provide the only support service that offers information to parents of children with all kinds of birth defects. We have recently been listed as a service to the handicapped in the Department of Education's "Directory of National Information Sources on Handicapping Conditions and Related Services".

I know that our group is needed and wanted by families of children with birth defects. (I have stacks of letters supporting our efforts). I know that we can provide an important service. But, we need the basic seed money to get started. It will be difficult for our group to grow if we have to wait and hope we will get enough donations to send out the next newsletter.

If you are aware of any federal programs that might offer some assistance with funding for our work, could you direct us to the appropriate program on department.

Thank you for your consideration of this letter and our request.

Sincerely,



Betty Mekdeci