

January 19, 2022

The Honorable Shane E. Pendergrass
Chair, Health and Government Operations
241 Taylor House Office Building
6 Bladen Street
Annapolis, MD 21401

The Honorable Joseline A. Pena-Melnyk
Vice Chair, Health and Government Operations
241 Taylor House Office Building
6 Bladen Street
Annapolis, MD 21401

Re: Testimony in Support of HB109—Jennifer Payne 1/19 at 2:30 p.m.

Appendix to Testimony of Jennifer Payne:

A dialogue with Carole Weiland, United States Senator Paul Sarbanes, and the State of Maryland illustrating the impact of withdrawing federal funding from Maryland's NBS program circa 1982.

Respectfully submitted,

/s/

Jennifer Weiland Payne, PharmD, MAPP
Independent Advocate, Adult with PKU
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United States Senate

WASHINGTON, D.C. 20510

October 18, 1982

Mrs. Carole Weiland
15064 Joshua Tree Road
Gaithersburg, Maryland 20878

Dear Mrs. Weiland:

Thank you very much for getting in touch with me to express your concerns regarding Maryland's PKU program. As one who has been a consistent and vigorous supporter in Congress of measures designed to ensure that adequate and affordable health care is available to all Americans, I greatly appreciate your taking the time to share your thoughtful and well-considered comments and personal experience with me. In order to be of assistance to you, I have contacted the appropriate officials of the Maryland Department of Health urging a careful review of this situation. You can be certain that I will be in touch with you as soon as I receive a response.

As you may know, I have strongly opposed the Reagan Administration's budget cuts which have such a detrimental effect on the health and well-being of our citizens. I share your strong commitment to the continuation of effective health care programs for the citizens of our nation, and want to assure you that I will continue to do all I can in the Senate in this most important area.

With best regards,

Sincerely,



Paul S. Sarbanes
United States Senator

PSS/jhl

United States Senate

WASHINGTON, D.C. 20510

November 18, 1982

Mrs. Carole Weiland
15064 Joshua Tree Road
Gaithersburg, Maryland 20878

Dear Mrs. Weiland:

Following up on our previous correspondence regarding budget cuts in Maryland's PKU program I am enclosing a copy of a letter which I recently received from the Maryland Department of Health and Mental Hygiene in response to your comments. I hope that the information provided will be helpful in answering your questions about this matter.

Please do not hesitate to let me know if there is any way in which I might be of further assistance.

With best regards,

Sincerely,



Paul S. Sarbanes
United States Senator

PSS/jhl
Enclosure

4 October 1982

Senator Paul Sarbanes
2327 Dirkson Bldg.
Washington, D.C. 20510

Dear Senator Sarbanes:

I wrote to you sometime ago and I am very happy to say that you were most helpful and I hope that will apply in this case also.

I am writing on behalf of two Maryland State Dept. of Health employees (in the Baltimore offices), Mrs. Lib Walker and Mrs. Sue Crosby. They work with children who have a hereditary genetic disease called PHENYLKETONURIA (PKU). PKU children lack an enzyme in their bodies which is responsible for breaking down an amino acid called phenylalanine. Fortunately, this particular disease isn't fatal; it is controlled by a special low protein diet and a regular blood test. If a child isn't diagnosed properly in the very first few weeks of life and put on the diet immediately, the phenylalanine builds up and causes retardation. Unfortunately, there have been cases where the child wasn't diagnosed early and the result is that the child is retarded. Therefore, it is very important that the diet be controlled and monitored and a regular blood test taken (which determines the phenylalanine content in the blood). If it is too high or too low, the diet is adjusted accordingly.

I have two children with this disease (the oldest a girl 9 years and a boy 7 years). Fortunately, due to the immediate response and quick action on the part of the pediatrician and the PKU Program of Maryland, my children were caught early in life and put on the diet immediately. I am very happy to say they have grown normally and do above average work in school. No one would ever know that they have this disease by looking at them; the difference shows when we are at the table for a meal and their plates do not have the same food as the others in the family. Their progress has a great deal to do with the work that Mrs. Crosby and Mrs. Walker do.

Mrs. Walker is a nutritionist and it is to her we go for advice when we have questions regarding the diet. She has been coming to our home for nine years and adjusting the children's diet to keep it under proper control (in accordance with the children's growth). She is always available and many times we have had to call her at her home for advice. She has been very helpful and gone above and beyond the call of duty. When our third child was born she and Mrs. Crosby came to our home the same day we returned from the hospital and took a sample of our child's blood. I told her how anxious I was and that everytime the phone rang I thought it was going to be the doctor telling me that the test was positive. After leaving our home she and Mrs. Crosby took the blood sample to the laboratory in Baltimore and asked the technician if he would do the blood test right away - he complied - and she called immediately to tell us the good news - that our third child didn't have the disease. This saved us days of worry and anxiety. Mrs. Walker has been with the PKU program for 18 years.

Mrs. Crosby is a nurse. She administers the blood tests each month. She makes the blood test out to be more of a game than a medical test, which is imperative to the children's well being. Because of her kindly manner the children no longer fear the blood tests and she has become such a good friend to them (and to us). She is also one we can turn to for advice and help. She has never in 9 years failed to come to our home to administer the blood test, even at times when she wasn't in the best of health.

We have known both of these ladies for over nine years and they have become more than medical advisors; they have become good friends and more than that, a part of our family. I know this feeling is shared by the numerous other PKU families in this State.

This past week they came for the usual monthly visit but this time they had very distressing news. They informed us that as of December of this year they won't be making home visits anymore. Why? Because of budget cuts. Mrs. Walker (after 18 years of service) will still remain in the program but only available by letter or phone (which is not sufficient in most cases). Mrs. Crosby (after 15 years of service) will no longer be making home visits - she has been cut completely from the PKU program. After all of these years of dedication to PKU children and parents she will have to start in a new field.

Any parent who has a child with any type of disorder, especially one that the child must carry with him throughout life finds it very heartbreaking. The first year of life for a child of this type is very difficult for the parent and is a learning experience and a time for adjustment to the fact that your child isn't like other children. At times like this the parents need a kind face and kind words and compassion; they need someone they can turn to. Mrs. Walker and Mrs. Crosby fulfill this need. I know from personal experience! They have always been there when I needed them; especially in the beginning when it was so important to me. I looked forward to and counted the days until their next visit. I always had so many questions and fears about my child's growth and mental well being. They were always very understanding and compassionate. If their jobs are cut from the program this one on one relationship won't be there and I just can't stress the importance of it, especially for parents who have just been told their child has a hereditary disease. That news is so devastating to a parent and without Mrs. Crosby and Mrs. Walker, they won't have anyone to communicate with on a personal basis; only telephone availability.

By these home visits Mrs. Walker and Mrs. Crosby can see the progress the children are making and know that they have been a significant part of that progress. This is very rewarding. They have personal relationships with all of their "children".

Since I am a PKU parent and know about the PKU program in other states, I can honestly say that Maryland probably has the best program in the country and I am very grateful that our children were born here. The following are some of the reasons why Maryland has such a marvelous PKU program.

- (1) Mandatory diagnostic newborn screening (which prevents retardation when diagnosed in the first weeks of life). Some states do not have this.
- (2) The home visits (which include advice on nutrition and regular blood tests so that the parents do not have to take the children to a hospital or clinic).
- (3) Yearly psychologicals and yearly physical exams for the PKU child.
- (4) Yearly meetings of parents and medical personnel to keep us abreast of current PKU developments.
- (5) Availability of services to children and parents.

Up to this point all of the above services have been free of charge. I understand that as of 1983 we will still have some of these services but the costs will be to the parents which will run into quite a bit of money.

There are societies and organizations for every kind of disease except PKU; all you have to do is look in the phone book (March of Dimes, Heart and Lung Disease, Cancer Institute, Muscular Dystrophy, and the list goes on.) These organizations are there to help and in most cases treatment and advice are given freely. There is no such organization for PKU. That is why we rely so heavily on Mrs. Walker and Mrs. Crosby. If they are cut from the program who can we turn to? They have even been so gracious as to give out their home phone numbers when there is a medical problem and a doctor can't be reached. I also understand the above services are all endangered; in fact, the entire PKU program is in jeopardy. Please help us keep it alive and active by sufficient funding.

I can't believe that the budget is so tight that Mrs. Walker's and Mrs. Crosby's services must be cut from the program. The purpose of this letter is to keep them in their present capacity. It is because of them that the program is successful. They are a vital part of it and if we lose them our children will be losing so much more.

What is the State doing with the money that they supposedly are saving by eliminating these services? Is it put into another program? What is the dollar difference in keeping them on in their present positions versus the new positions? I am sure it is such a minute amount that the budget could be adjusted accordingly.

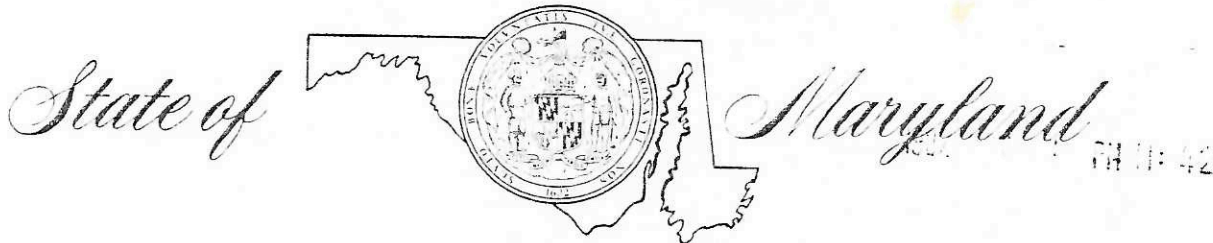
I am sorry to have gone on so but I think it is imperative that you know exactly how important these ladies are and the importance of the entire PKU program. I would like a response at your earliest convenience as December isn't far away and that is when their present positions will cease to exist. If at all possible I (and possibly other PKU parents and children) would like an audience with you to discuss this further. This will be affecting quite a number of families in the State and this certainly is worthwhile to do a little research and investigating.

Thanking you in advance,

Mrs. Carole Weiland

Mrs. Carole Weiland
15064 Joshua Tree Rd.
Gaithersburg, Md. 20878

(301) 279-7196



OFFICE OF THE SECRETARY
DEPARTMENT OF HEALTH AND MENTAL HYGIENE
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Harry Hughes, Governor

Charles R. Buck, Jr., Sc.D. Secretary

November 9, 1982

The Honorable Paul S. Sarbanes
United States Senator
2327 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Senator Sarbanes:

In response to your letter of October 18, 1982, I have asked the Preventive Medicine Administration for information about the PKU Program.

As I understand from Mrs. Weiland's letter, her primary concern is for the quality of services which will be available to families of children with PKU and other hereditary metabolic disorders discovered by Maryland's New-born Screening Program when Federal funds are withdrawn. Specifically, she is requesting that Mrs. Lib Walker and Mrs. Sue Crosby continue performing the same jobs which they have carried out with dedication for many years. The Department shares Mrs. Weiland's concerns about quality of services and certainly understands her uncertainties about the upcoming changes in the program.

The intensive home visiting, blood-drawing, and dietary monitoring services described by Mrs. Weiland were part of a detailed study protocol beginning in the early years of Maryland's PKU program. At that time, Maryland was part of a multi-state collaborative study which was necessary to clarify the effects and benefits of dietary treatment. Careful monitoring of blood levels and developmental milestones was available only through the two specially trained professionals under the federally supported PKU demonstration program. NO

Through Maryland's participation with other states, the collaborative study has now followed sufficient children to carefully verify the safety, efficacy, and success of PKU treatment. As a result, the intensive, home-based services which were necessary for the study will now be restructured. This must be done to accommodate termination of federal PKU funding and to concentrate Mrs. Walker's nutritional expertise on the more vulnerable new infant cases. These infants will receive home services until their condition is stable and their families understand the therapeutic regime.

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It is true that Mrs. Walker and Mrs. Crosby will not make home visits to the Weilands anymore. Such parents of older children will now have the option of either learning to draw a small blood specimen themselves (the state will provide an "autolet" to make this procedure as simple as possible) or using their local health department to have the specimen taken at regular intervals. No

The results will be forwarded to Mrs. Walker who will be stationed centrally in the State Health Department in Baltimore. She will monitor the blood levels of phenylalanine on all children and make diet changes as appropriate. She will be readily available for consultation by telephone, which is not the case at present. Because of this change, results should be communicated to parents more quickly than in the past. It is the Department's feeling that using Mrs. Walker's experience and expertise in this way is far more efficient than having her spend alot of unproductive time in transit, which also results in her being unavailable to other families needing consultation.

Mrs. Crosby will not be out of the PKU Program entirely[?]. However, through her work in the PKU Program she too has gained a great deal of experience and expertise in dealing with parents of children with newly diagnosed hereditary conditions. The Division of Hereditary Disorders has been given the responsibility of implementing HB 351 - Sentinel Birth Defects Registry. An important part of the program is to provide parents of infants with one of twelve birth defects with information about available services and resources, such as the parents groups mentioned by Mrs. Weiland. Mrs. Crosby is needed to help train the hospital personnel who will then be able to serve distressed parents of a newly diagnosed infant with a birth defect. Again, it is the Department's feeling that particularly in these times of reduced funds, it must use its resources to its best advantage. But for families accustomed to having Mrs. Crosby and Mrs. Walker visit them at home, these changes will be understandably difficult.

Speaking to Mrs. Weiland's "reasons why Maryland has such a marvelous PKU program," we wish to emphasize that we agree with her that the program is among the best, nation-wide. The Department is committed to maintaining the Newborn Screening Program and concomitant follow-up services. These follow-up services will include monitoring of diet, nutrition advice, yearly meetings of parents and medical personnel, and the potential for local health department, home or clinic services.

Local health departments have agreed to expand their role, and the Division of Hereditary Disorders will help train staff so they can counsel families and collect bloods. Whenever possible, families will be seen at the genetics outreach clinic closest to their home. This will save them some inconvenience of travel and some expense. It is expected that, within the next year in compliance with state law, fees will have to be instituted for psychological services. Ways of assuring third party payments for these services are being explored in an effort to reduce the families' out of pocket expenses to the minimum.

The Honorable Paul S. Sarbanes


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Mrs. Weiland has beautifully described the benefits of comprehensive child health care including home health services. It is Preventive Medicine Administration's plan to strengthen such services through local public and private health resources for which additional state or federal funds may be required. These have been identified in the Department's FY 84 plan priorities, but funding is presently uncertain.

I hope that the above information is helpful to you. We will be happy to provide you with further information if necessary.

Sincerely,

A handwritten signature in cursive script, appearing to read "Fran Tracy".

Fran Tracy, Director
Office of Government Relations

FT:psp