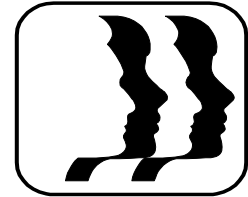


# CONCORDANCE

Volume 1, No. 4



Research into the Causes of Schizophrenia and related illnesses  
Western Psychiatric Institute and Clinic -- University of Pittsburgh

Hello again from Pittsburgh. In this fourth edition of our newsletter we give an update on progress, make an appeal for your help in locating affected sibling pairs, and re-address the issue of getting the results of our laboratory tests. The end of May will mark the completion of our first year of the project. We hope you enjoy this newsletter, and find it informative.  
--Patrick Reitz, Project Coordinator

## **HELP WANTED: AFFECTED SIBLING PAIRS NEEDED!**

As many of you are aware, our study is seeking involvement by families **with pairs of affected siblings**—that is, families where at least two siblings are both individually diagnosed with either schizophrenia or schizoaffective disorder. For example, an eligible family might consist of a set of parents with a daughter diagnosed with schizophrenia and a son diagnosed with schizoaffective disorder. Or, the daughter and son could both be diagnosed schizophrenia, or both schizoaffective. To be eligible for our study, affected sibling pairs are not required to have parents participate, also. The siblings alone can participate and constitute a “family.” However, participation by one or both parents is still very desirable, whenever possible. (PLEASE NOTE: This analysis is not intended to identify parents who have passed down ‘bad genes’ to their children).

We are seeking participation from affected sibling pairs because particularly useful genetic analyses can be performed with sibling pairs. However, families with affected sibling pairs are not as common as families with one ill offspring (which is merciful fact, even if it makes our research harder). It will be much more difficult for us to involve the target number of 300 sibling pairs during our 5 year study than to meet our goal of involving 300 families with one affected person.

**WE NEED YOUR HELP!** Please, if you know of anyone who is affected with schizophrenia or schizoaffective disorder, and has a sibling who is also affected with one of these illnesses, mention our study to them. Pass along to them our contact information (see box , next column) so they can inquire more about the study, or even volunteer if they are interested.

In partnership with you, we believe it is possible to meet our project goals and create knowledge that could lead to better treatment and possibly even prevention of these debilitating illnesses. Please call us!

### **To Contact Us:**

Call toll free: 1-800-994-8182  
Fax: 412-624-0446  
Dr. Nimgaonkar: 412-624-0823

### **Visit our web pages:**

Schizophrenia study: <http://www.pitt.edu/~nimga/>  
Bipolar study:  
<http://www.wpic.pitt.edu/research/neurogen/>

### ***Our Policy Regarding Releasing the Results of Laboratory Analyses***

At a recent conference of our entire staff, several of our research associates mentioned that a lot of families have been asking for the results of our laboratory tests of their donated DNA. In the previous issue of *Concordance*, we mentioned that although participants in the study have a right to these results, we caution families about asking for them. Since this seems to be a continuing issue of concern for both families and staff alike, we thought we would go into more detail about it here.

As it says in the consent forms for the study, participants have the right to request the results of the tests we perform in our research laboratory. However, given our current understanding of the genetic basis of mental illness, these results as such will probably not provide the type of information you are looking for. To be more specific:

(1) **The tests we perform cannot tell you about any family member's risk for developing schizophrenia or related illnesses.** At this point, we have not even begun the laboratory analyses. For economical reasons, it makes most sense to begin analyses only after a large number of samples have been collected. We have not quite collected enough samples yet to begin. Just as importantly, the planned analyses are intended only to narrow down the areas on chromosomes where the genes involved in psychotic illnesses may be located; we cannot at all say that a particular gene or group of genes are the ones that make you prone to illness. We simply do not have that knowledge yet. Thus, if you are thinking of getting the results to find out the risk of illness for yourself or relatives, you will not be able at this point to use them for that purpose.

2) The tests we are doing are for research purposes only. The laboratory reports you receive would be related in very technical language which may not be meaningful to you.

Furthermore, because our laboratory is for research purposes only, the results that come from it cannot be used by any doctor as a basis for treatment decisions for any illness. Physicians by law can use only test results from laboratories certified for that express purpose to help them make treatment decisions.

3) **The results could be very distressing to you.** We consulted an expert in the ethical aspects of genetic research, Dr. David Shore of NIMH, regarding this issue. He gave a clear warning that releasing preliminary laboratory results to participants could lead to conclusions that are often "harmful, misleading, or wrong." Again, this is because the current knowledge about the genetics of mental illnesses is quite limited compared to other medical disorders.

Given all of the above, we have decided that the most ethical policy to follow is to release laboratory results to participants *only* after the following things have been achieved: 1) all of our lab analyses are complete; 2) the general results of our study have been presented before the scientific community for criticism; 3) our results have been replicated by other researchers; 4) a formal protocol for genetic counseling related to mental illnesses has been developed. When all these things have been accomplished, sufficient knowledge and structure will be in place to allow for accurate, responsible interpretation of lab results.

We hope you understand our caution, and we ask for your patience. In future issues of *Concordance* we will update you on the study's progress, and provide any new information regarding our policies on releasing lab results.

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## **Dr. Frederick J. Frese speaks in Johnstown, PA** by Erin King, Research Associate

*This item is a bit dated, but we thought it was too good not to include.*

In November, at the Johnstown AMI annual banquet, I had the pleasure of hearing Dr. Frederick J. Frese speak. He is eminently qualified to talk about the ravages of severe mental illness: He is a clinical psychologist who has served Director of Psychology at Western Reserve Psychiatric Hospital; he has taught at many different universities, and has served on the advisory reviewing boards of five professional journals, including Schizophrenia Journal. He currently serves as Second Vice President of its National Board of the Alliance for the Mentally Ill, and as a consultant to the Department of Veterans Affairs on a project to improve clinical practice.

Dr. Frese has also been diagnosed with schizophrenia.

He talked about the time, when, as a young Marine Corps officer, he became paranoid about government conspiracies. He talked about wandering the streets led only by the number three - which street names had three syllables? Where was the holy trinity church? Which street addresses were multiples of three? His words were infused with the intensity of first-hand experience. They invited us to not only understand the loosened logic of a person with schizophrenia, but to, for a moment, adopt it as our own. .

The most important point Dr. Frese made, however, was not stated in his talk. His most important statement was his own self, the statement of a life lived without regard to the limitations schizophrenia is supposed to impose. Despite being in and out of mental hospitalizations, Dr. Frese managed to earn a degree in business management in addition to Masters and Doctoral degrees in psychology from Ohio University. Of all of his functions - advocate, healer, educator, the most important is the most personal: that he serves as an inspiration and example that life does not end with mental illness.

***Q: I want to participate in the study, but my parents live in another state. Can I still be involved?***

***A: Yes. Although we prefer to interview persons affected with illness face to face, we often do interviews with parents over the phone. Also, if a parent is willing, we can arrange to have their blood drawn by their local doctor or lab, and shipped to us. We send supplies for the blood draw and pay any lab fees to get this done. We will even do this for parents who are separated and living in two different places.***

***Q: I want to participate, but my sibling, who is also affected, lives across the country. Do you still want me to participate?***

***A: Definitely yes. As mentioned elsewhere in this newsletter, pairs of affected siblings are difficult for us to locate. In this case, we would first interview you locally, and then plan for a future trip to interview your sibling in person. Over the course of the five year project, we expect clusters of families to appear in different parts of the country, probably grouped around the same metropolitan areas. Your sibling may end up living next to other people we would like to interview. Or perhaps one of our staff will be visiting that part of the country for another reason. In either case, we will fly someone to interview your sibling at some point in the next several years. If necessary, we would make a separate trip to do so. So please, let us know your situation before giving up.***