What You Thought About Our Surveys

Many twins and parents of twins wrote comments at the end of recent surveys. Your suggestions were very valuable to us, and we plan to use many of them as we embark on new studies and create new questionnaires.

• Most enjoyed filling out our surveys, were very interested in our research, and even felt that the sur-

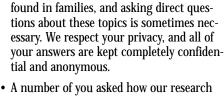
veys helped you to realize how special your families are.

· Some of you felt that the different surveys you have received asked the same types of questions. We understand how important it is to make our surveys as short as possible. However, we must sometimes ask questions about a specific problem or

experience more than one time or in very similar ways. The purpose of this is to study health conditions over time (a "longitudinal" study) which helps us to learn how behaviors or health conditions develop, and how they change throughout our lives.

either nega tive or too

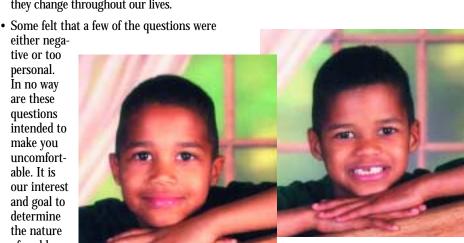
personal. In no way are these questions intended to make vou uncomfort able. It is our interest and goal to determine the nature of problems



pertains to twins. Twins are a special and

unique resource because they help scientists to understand the relationship between the environment and heredity (genes). Even though twins are the same age and usually grow up in the same household. their experiences can differ greatly. Since identical twins share all the same hereditary material (DNA), whereas fraternal twins do not, comparing the differences and similarities in identical and fra-

ternal twins is a powerful way to determine the causes of our health and behaviors.



The Importance of DNA

In some of our studies we will be asking participants to provide a sample of their DNA. Looking at DNA samples will allow us to search for individual genes that affect the risk for developing health and behavior problems. We need hundreds of samples of DNA from families to understand the causes of

disorders. Study of these DNA may lead to improved prevention and treatment of some disorders. As with all data from our studies, results of DNA analyses are held in strict confidence. We hope you will be able to help us in this critical area of our research.

Did you know that...

- Approximately 2,500 sets of twins are born in North Carolina and Virginia each year.
- · Virginia & North Carolina both have mother's of multiples clubs established for the purpose of uniting mothers of multiples and providing them with support, ideas and educational information. For more information on North Carolina clubs contact: Dian Liek at(803) 547-5789 or Barbara McPherson at (910) 799-0942. For information about Virginia clubs, please contact the National Organization of Mothers of Twins Clubs (NOMOTC) at (505) 275-0955.
- The Multiple Births Foundation of North America invites you and your family and friends to join the fun in June of 1998 for the Annual Multiples Family Day at Kings Dominion Amusement Park in Virginia. Multiples from across the mid-atlantic states come together to celebrate their unique status as twins, triplets and more. For more information and to order your tickets, please contact: Multiple Births Foundation of North America, PO Box 146, Wake Forest, NC 27588, (919) 556-1385.

We are interested in your ideas...

- You might wish to check out our new World Wide Web site on the Internet and tell us what you think. We are looking for Web Page ideas. Our address is: http://views.vcu.edu/~twinreg/
- We would like a new name for our newsletter. Please send us your creative ideas and you may see your newsletter name in our next edition!
- Your ideas and comments can be called in to 1-800-URA-TWIN (1-800-872-8946). Please don't forget to leave your name and phone number. Please also call or write with any address, telephone number, or name changes. Our mailing address is: The MidAtlantic Twin Registry, PO Box 980003, Richmond, VA 23298-0003.

A Special Thank You!

We want to thank all the families that have sent in photographs of their twins. You can see some of these pictures in this newsletter and on our website. We love to receive your pictures and will show them off whenever we can (we will be unable to return any photographs). Please continue to send photos of yourself and your twin (adult as well as young twins) to the address provided below. Please remember to include full names and nicknames on the back of the photographs.

Important Notice



P.O. Box 980003, Richmond, VA 23298

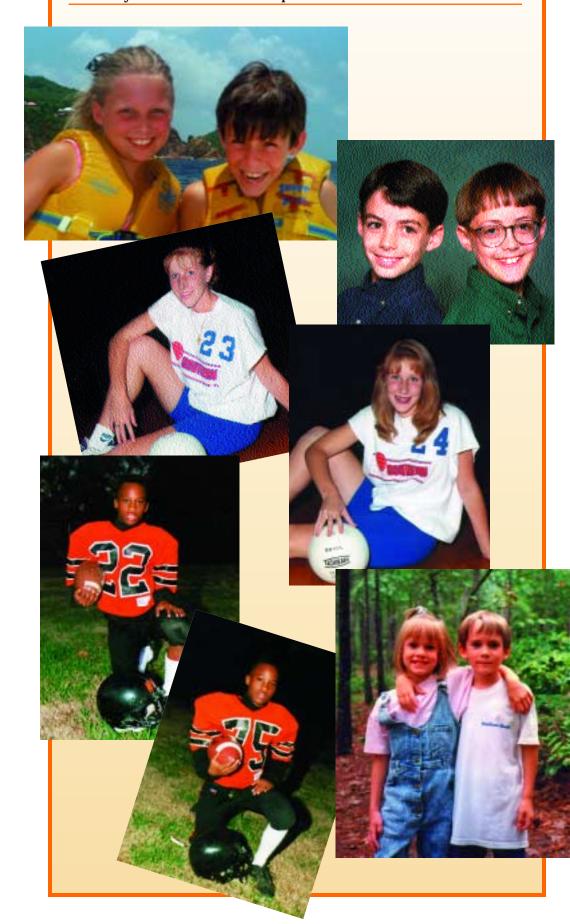
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MidAtlantic Twin Registry

A Family Newsletter for Multiples in VA & NC

Fall/Winter, 1997



A Message From the Directors of the MidAtlantic Twin Registry...

hank you for being a part of the MidAtlantic Twin Registry. As you may know, twins and their families can play an important role in helping scientists understand the impact of genetic and social factors in our lives.

Our twin studies concern improving the quality of life for families by identifying factors that affect health and development. It is only through research of this kind that many basic questions are answered.

We hope this newsletter will give you interesting and valuable information about our research, and about twins, their families, and related topics. We greatly appreciate and look forward to your continued participation.

Sincerely,

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Linda Corey, PhD

Lenn Murrelle, MSPH, PhD



Our new home is in the Virginia Biotechnology Center, in Richmond, VA shown here

We've Merged the Twin Registries

We are excited about the recent merging of the North Carolina Twin Registry with the Virginia Twin Registry. The new registry consists of all the twins born and living in these states who are willing to help medical

The Virginia Twin Registry is a populationbased panel of twins and other multiples that was established in 1980. It currently includes over 13,600 twin pairs who were born in Virginia between 1915 and 1994. The North Carolina Twin Registry was established between 1990 and 1995 in a joint effort of The University of North Carolina at Chapel Hill and Virginia Commonwealth University. It consists of approximately 12,000 twin pairs born in North Carolina since 1913. This combination makes The MidAtlantic Twin Registry one of the largest twin registries in the world!

Twins and their families were identified for the registry by using publicly available birth records, public driver's license information, and through public and private school records. This information was made available only for the purpose of medical research.

Establishing an Infant/Preschool Twin Registry

We are now in the process of establishing an Infant/Preschool Twin Registry, which will be comprised of twins from birth through five years old. An effort is currently under way to locate the parents of all twins born in North Carolina or Virginia between January 1, 1991 and December 31, 1996. We will mail a short survey to these families inviting them to participate in our research.

An Update on our Studies

The Virginia Twin Study of Adolescent Behavioral Development (VTSABD)

The VTSABD is a long term project on child development that began in 1989. More than 1,400 twin pairs between the ages of 8 and 17, and their parents, completed home interviews and questionnaires during the first phase of the

project. More than 1,200 families continue to be involved in the third and fourth phases of the project. These phases are critical to our research, and we look forward to your continued support.

Findings from this study suggest that genetic factors influence risk for a wide range of adolescent behavioral problems, including conduct disorder, depression and attention deficit hyperactivity disorder. Of particular

interest in this study are the genetic and social factors contributing to the risk for the use of alcohol among older children. Findings suggest that good communication among family members seems to be a protective factor against adolescent use of alcohol, especially more frequent alcohol use.

Seizure Study

Epilepsy and other seizures are common health problems. Although there is very strong evidence that hereditary factors are important in determining whether or not someone will have certain types of epilepsy, little is known about why seizures occur. Several years ago we began a study to determine if inherited factors are important in determining risk for seizures. Many of you have already filled out questionnaires for us. The information that has been provided by more than 500 twins and their families in Virginia who participate in the study has provided important insights about seizures and we are extremely grateful to each individual who has taken part.

Our preliminary results suggest that hereditary factors play a role in whether or not a person has seizures.

As with any scientific study of this type it is extremely important that we have as many individuals participate as possible. Therefore, we will continue to mail surveys to twins and their families in an effort to increase our knowledge about this important health problem. If you receive a survey, please indicate if anyone in your family has had a seizure. If you have filled out a survey for us before, but you have new or additional information about seizures in your family, please let us know about that as well.

The Virginia-North Carolina African American Adolescent Twin Study on Health

The Virginia-North Carolina African American Adolescent Twin Study on Health is in it's third year and will continue through the year 2000. We now have over 150 families that have participated in this telephone interview project. The purpose of this study is to examine

possible harmful and protective factors that relate to cigarette smoking, alcohol use, use of chewing tobacco and other behaviors.

So far we are finding that many teenagers have experimented with cigarettes and alcohol, some more than others. We hope to show that spirituality, wellness behaviors (like exercise), and family support are associated with greater overall healthy

behaviors in teenagers.

The Stress and Coping Project

The Stress and Coping project, conducted using the Virginia Twin Registry, includes a family of studies whose goal is to understand the role of nature and nurture in influencing the ways we deal with adversity. Three recent developments in these projects are noteworthy. First, we completed the 4th wave of interviews with members of female-female twin pairs studied since 1986. These assessments focused on the use of alcohol and other substances. We know almost nothing about how genes and environment contribute to the risk for substance use and abuse in women. Analysis of this data will begin soon and we hope to gain some important insights into these critical problems.

Second, we finished the first wave of our newer study of male-male and male-female fraternal pairs. We interviewed over 6,800 twins and we are very grateful for everyone's help in this important project. We will be using the results of these interviews to help us understand how nature and nurture contribute to problems with depression and alcohol use and abuse in men. This project will provide key insights into why men and women differ in the ways in which they cope with stress. Under adversity, men are much more likely than women to use alcohol and drugs while women are much more likely than men to develop anxiety and depression. We will be re-contacting twins in this study over the next year to ask their further cooperation for a second interview which covers other critical areas of psychological functioning such as anxiety disorders, drug and tobacco use and personality.

Study Updates

Third, while our previous twin studies have focused on Caucasian twins only, we will soon be starting our first study focusing on African-American and other minority twins born in Virginia. We hope to clarify the degree to which genetic and environmental factors that influence reactions to stress and substance use and abuse are similar in the major ethnic groups in the Commonwealth of Virginia.

The North Carolina School Age Twin Study

We recently mailed a survey questionnaire on health and development to the mothers of nearly 2,000 twins aged 6-18. We also mailed a survey to approximately 1,000 twins between 12 and 18 years of age.

One aim of our study is to examine protective and risk factors that may influence adolescent behavior and development. We hope to identify social and environmental conditions in an adolescent's life that protect them against such behaviors as substance use and abuse.

The family environment, such as family relationships, communication, and values, is

known to have an association with adolescent behavior. Of the 658 mothers who responded to our questionnaire, 84% reported that they often felt a feeling of togetherness in their family. The majority also reported that certain religious/spiritual beliefs and practices were either important or very important in their lives. Of the 575 adolescents who responded, 81% felt that religion was either important or very important in their lives. Regarding their family, most adolescents felt that a lot of the time their mother and father made them feel wanted. We will examine qualities like these to see if they protect children against unhealthy behaviors

We wish to thank all the families and twins who have participated in our studies! Look in future newsletters for continued study updates, as well as information about scientific publications discussing our research findings. If you have any questions, or would like to be included in any of these studies, please call 1-(800)-URA-TWIN.

New Studies

Thanks to Those Responding to New Health Study

About three weeks ago we mailed a fourpage health survey to twins 18 and older. We are very pleased by the quick response of thousands of twins who have already returned the survey!

Your responses to this important survey will help us understand the causes of many common emotional, behavioral, and medical problems! It is crucial that as many twins as possible return the survey completed.

If you have not yet returned your survey, we would still like to hear from you. Please take the time to fill it out and return it to us as soon as possible. Be assured that all of

your responses will be kept completely confidential. If your twin is deceased, your responses are still helpful to our research.

Twin Eye Disease Study

Dr. Johanna Seddon of Harvard Medical School and Massachusetts Eye and Ear Infirmary is conducting a study to identify the risk factors for macular degeneration, an eye disease affecting the center of the retina. This study is recruiting male twins with macular degeneration who are 55 years of age or older. If you and your twin brother are interested in participating in this study, please contact Sandra E. Lee at 1-800-306-TWIN (or 1-800-306-8946). We look forward to hearing from you!

Go To New York!

If you love to travel and are in good health, you and your twin may qualify for an ongoing nutrition study at The Rockefeller University in New York City! Same sex, non-identical, 18-75 year old twins will be paid \$1000 each for completing the 4-week study. All meals and travel expenses are provided. For more information contact Elizabeth R. De Oliveira, M.D. at (212) 327-7676.

