## Resources for Twins and Their Families

### **Books on Twinning**

The Twinship Sourcebook: Your Guide to Understanding Multiples, compiled by the editors of Twins Magazine.

by the editors of Twins Magazine. This book contains about 30 short essays, covering a wide range of issues of interest to twins, their families, and friends. It covers such topics as temperament and personality, importance of twin type, and twins around the world. The book can be purchased directly from *Twins Magazine* for \$14.95. You can place a phone order by calling (888) 55-TWINS.

Twins and Higher Multiple
Births: A Guide to their Nature and
Nurture, written by Elizabeth
Bryan. This book is more academic
in nature and covers such issues as the biology of twinning and the delivery of twins, as well as examining twins from the early years of life through early adulthood. You can order this book through your local bookstore.

### **Books For Kids**

Mitch & Amy, by Beverly Cleary with illustrations by Bob Marshall. Nine year old Mitch and Amy come to understand how special it is to be twins even though they don't always get along. It is aimed at children eight years old and older. Published by Morrow, it sells for \$13.05.

New One and Project Wheels, by Jacqueline Banks, are targeted at twins ten and older. The stories of African American sixth grade twin brothers take place in Kentucky and revolves around school, family and friends, and the very real issues of growing up. The books are published by Houghton Mifflin and sell for \$13.95 each.

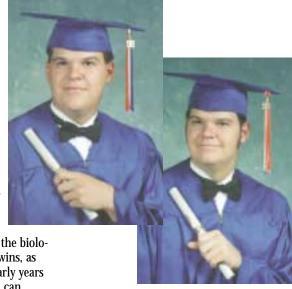
#### Web Sites

If you love to "surf the net", the following web sites may be of interest to you:

http://www.multiplebirth.com
This is the website for The Center for
Study of Multiple Birth (CSMB), which is
recognized internationally as a unique
resource for research and information about
the causes, effects and problems of multifetal
pregnancy. Their mission is to promote and
advance the health of women and children,
particularly multiples, through education,
research and public service.

### http://www.nomotc.org/

This is the website for The National Organization of Mothers of Twins Clubs, Inc., a support group for parents of twins and higher order multiples. Here you can find an abundance of information regarding resources for families with multiples.



http://www.fourdee.com/4d\_ref.html

This site has multiple birth support information, including the names, addresses and contact information for a variety of twin organizations and resources (clubs, associations, services, magazines, etc.)

### http://www.twinspace.com

This is a web site about twins containing information about research, twin facts, organizations, books, parenting information, and more.

### Participants Needed for New MATR Studies

Two new research studies are being conducted by Dr. Colleen Jackson-Cook of Virginia Commonwealth University. The studies will provide important information about genetic factors in common types of birth defects, cancer, and the normal aging process. Pairs of male twins at least 21 years of age, and females pairs 45 years or older are needed.

Participants will receive, FREE of charge, information about their chromosomal makeup (\$450 test value) and about whether they are genetically identical or fraternal twins (\$250 test value). All information will be kept CON-FIDENTIAL, and the overall study results will be made available to participants when the research is complete. For more information please call toll free at 1-800-URA-TWIN and mention your interest in Dr. Jackson-Cook's studies.

Thank you for your help!

### Don't forget to visit our website!

You can find it at:

http://views.vcu.edu/~twinreg/

## Did you know that...

- Although Saint Augustine recognized in the 5th Century AD the importance of studying twins, scientific twin studies only began in the latter quarter of the 19th century. Most prior knowledge about twins had been based on folklore and myth.
- Identical twin brothers Mark and Scott Kelly are NASA's only twins. They are also the only siblings ever to both be selected as NASA astronauts. The Kelly's are both Navy Lieutenants and pilots, and are currently training to become astronauts at the Johnson Space Center in Houston. Texas.
- Female identical twins are more likely to participate in research than male identical or fraternal twins, even though they are not the largest group of twins in the population. However, all types of twin pairs are needed for medical research. Thank you to everyone who has participated!

## A Special Thank You!

We wanted to thank everyone who suggested a new name for our newsletter. We chose "Twin Matters" for three reasons. First, our newsletter addresses many issues or "matters" related to twins and twin research. Second, we liked the name because of the play on words the abbreviation for the Mid-Atlantic Twin Registry is "MATR", which we pronounce "matter". Finally, Twins Matter to us. Thanks again for your suggestions!

## Address Changes/Questions/Comments

Please let us know if you have moved, are planning to move, or if your telephone number changes. This will help us in our effort to send mailings and information to you in a timely manner. You can leave a message at 1-800-URA-TWIN or write to us at: The Mid-Atlantic Twin Registry, PO Box 980003, Richmond, VA 23298.

Your comments, suggestions and questions can also be called in to 1-800-URA-TWIN, or e-mail us at: twinreg@hsc.vcu.edu. Please don't forget to leave your name and phone number.

## Keep Those Pictures Coming!

Thank you to everyone who has sent in photographs. Please continue to send us pictures of yourself and your twin (adults as well as young twins), and remember to include full names and nicknames on the back of the photographs. We will use as many pictures as we can in our publications and website.

## MID-ATLANTIC *twin* STUDIES Medical College of Virginia of Virginia Commonwealth University

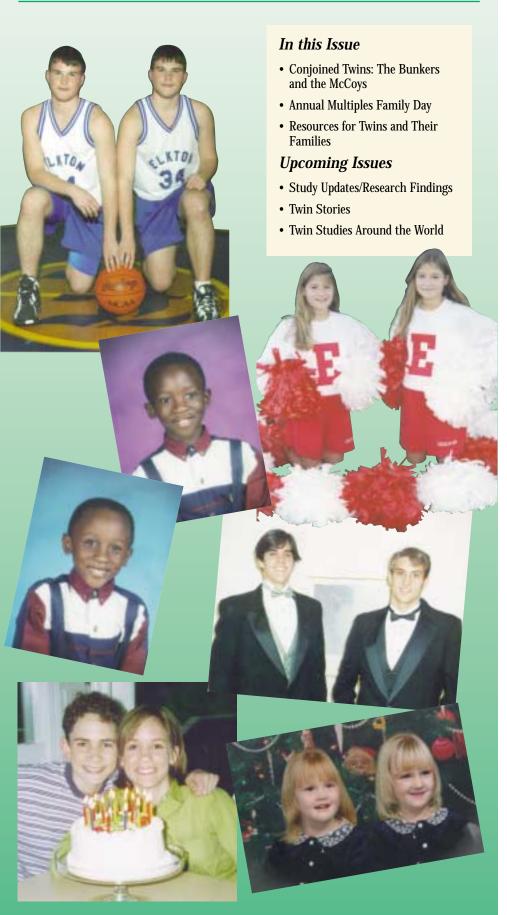
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# Twin Matters

A Family Newsletter from the Mid-Atlantic Twin Registry Volume II



## A Message From the Directors of the Mid-Atlantic Twin Registry...

hope you enjoyed our last newsletter. If there are topics you are interested in or would like to see in future newsletters, please let us know. It is important to us to keep our twin registry families informed and updated about our research and related

Research involving twins requires thousands of pairs and their families. Large numbers of people are needed for scientists to study health conditions and behaviors that are rare. Likewise, a larger number of participants permits scientists to apply their findings to the general population. For this reason, a number of countries around the world, including Australia, Belgium, England, Finland, The Netherlands, Norway, and the United States, have created large databases (registries) of twins.

Efforts to expand the MATR continue. We are pleased to report the addition of South Carolina to our registry. We look forward to welcoming many new South Carolina twins and their families, as well as new families of preschool twins in Virginia and North Carolina. The MATR is already one of the largest twin registries in the world, and with the addition of these new preschool and South Carolina families, over 50,000 twin fami-

lies could be enrolled. Thank you again for your support. Our research would not be possible without your generous help.

Sincerely,

H, PhD Linda Corey, PhD In helle

Lenn Murrelle, MSPH, PhD





McCoy twins lived in an era when separation was far less common, so they remained joined

## Who Funds Our Research

Since the creation of the twin registry in 1978, nearly \$20 million in federal and private grant funding has supported our research program. We receive the majority of our funding from the National Institutes of Health, including the institutes dedicated to heart, lung and blood disorders, neuroscience, mental health, drug abuse, alcoholism, and child health and development.

Private foundations, such as the Robert Wood Johnson Foundation, the John Templeton Foundation, and industry partners also support our research. To receive funding, each proposed study must undergo a careful and thorough review. Only research of the highest merit is funded.

### The VIPBG Staff

The MATR is maintained by scientists at Virginia Commonwealth University in Richmond. We are located in the Virginia

Institute for Psychiatric and **Behavioral Genetics** (VIPBG). The VIPBG staff represent many different fields and areas of expertise. Our staff of over 100 is made up of research scientists, including geneticists, psychologists, epidemiologists, medical doctors, as well as computer programmers, research assistants, fiscal technicians, study coordina-

tors, interviewers, laboratory technicians, data entry personnel, and other support staff. It is through the efforts of this multidisciplinary team that our important research is accomplished.

### Twin Stories

Some of the most famous twins, the Bunker and the McCoy twins, are associated with the Mid-Atlantic region. Both were pairs of "Siamese", or conjoined, twins whose lives spanned most of the 1800's.

Conjoined twins are joined together physically at some

point of their bodies. There is a great range in the degree to which the twins are joined, depending largely on which organs are shared. Some twins have undergone separation surgery in which both have survived. However, the Bunker and



## throughout their lifetime.

### The Bunker Twins

The term "Siamese twin" originates with Chang and Eng Bunker. They were born in Siam (which is now Thailand) in 1811 and were joined by a thick band of flesh connecting them at the chest. In 1829, when the twins were 18, a Scottish trader and a sea captain convinced the twins' mother that they would have a better life abroad. They spent the next eight years touring the United States and Europe. Chang and Eng gained a great deal of wealth and became worldly men with a sharp interest in learning and cul ture. In their travels they met Dr. James Calloway of Wilkesboro, North Carolina, who convinced them that they should include the North Carolina mountains on their itinerary. In 1837 they finally made their way there. Liking the area and the people, and growing weary of their travels, they decided to settle in North Carolina.

The Bunkers married sisters and had 21 children between them. Eventually the two families lived in separate houses due to the large number of children and some bickering between the husbands and the wives. Chang and Eng took turns living between the two households. Despite minor personality differences and occasional disagreements, the two brothers seemed to live in harmony with one another. They died in 1874 at the age of 63. Chang had been ill and although Eng had been in good health he died only hours after his brother.

### The McCoy Twins

Millie and Christine McCoy were born forty years after the Bunkers in July of 1851, and were joined at the hip. They were the daughters of slaves, Monemia and Jacob. They were originally owned by Jabe McCoy of Whiteville, North

Carolina, but they passed through many hands. Their last manager and legal owner was Pearson Smith.

Millie and Christine were kidnapped twice before they were ten years old, and during this time Pearson Smith's father and the twins' mother searched for the girls for three years. They were found in



England, where they were being exhibited by British showmen. Once recovered, Mr. Smith continued to exhibit Millie and Christine throughout Europe. They often appeared before royalty, and received many fine gifts. When they returned to the United States, they were hidden in the countryside near Spartanburg, South Carolina, to prevent them from being taken by Union troops during the Civil War.

Freed from slavery after the war, Millie and Christine decided to continue touring, and by the end of their career they had traveled throughout most of the United States. They knew seven languages, and were said to be bright and delightful women with beautiful singing voices, for which they were given the nickname "Carolina Nightingale."

According to surviving family members, Millie and Christine got along very well, despite the intimacy of their lives. They acquired great wealth and many souvenirs from their travels, but always returned to their birthplace, where they built a home. Unfortunately, in 1909 their home burned and they lost many of their treasures. It was at this time that Millie contracted tuberculosis. Christine's health remained good, but she died within 24 hours of her sister, after being given massive doses of morphine. It is said she sang and prayed that the end would come

## Conjoined Twins Today

### A Physician's Experience

Dr. John M. Templeton, Jr. is a pediatric surgeon who has participated in nine surgeries to separate pairs of conjoined twins. He is also the President of the John Templeton Foundation, which has provided generous funding for the Mid-Atlantic School Age Twin Study. After graduating from Yale and Harvard universities, Dr. Templeton complet ed his postgraduate training at the Medical College of Virginia in Richmond. He first worked with conjoined twins in 1974 after caring for and assisting in the separation of twins from the Dominican Republic.

The number of conjoined twins born in the United States each year is very small. Although not known precisely, Dr. Templeton estimates the number to be approximately 1 out of every 250-500,000 births, or about six conjoined pairs born per year.

According to Dr. Templeton, the decision to separate conjoined twins is made on a case-by-case basis. They should not be separated if the risk to their lives is too great and their condition is medically satisfactory while they are joined. The best time to perform a separation is when the twins are stable and in good physical shape, which is usually at three to six months of age. There are extreme cases in which the medical problems of the twins are so severe that one twin and then both twins begin to deteriorate and may die unless

an attempt is made to separate them.

For Dr. Templeton, the primary ethical considerations that must precede the separation of conjoined twins are "designed to emphasize the uniqueness of each set of conjoined twins and the maximum opportunity for survival with the maximum quality of life." Conjoined twins are usually so young that the decision to separate them is made by the family and the medical support team. When Dr. Templeton worked with the twins from the Dominican Republic, there was some concern they would suffer from "separation anxiety" since they were separated at 14 months of age. They were joined in the lower body, but each had two normal legs. Their separation was successful and they both adjusted very well.

In the case of the Bunker twins, Dr. Templeton believes they would have been easy to separate. Even at the time that Chang died, a tight cord could have been tied around their common point of connection. This would have stopped his brother Eng from dying and would have allowed for a successful separation. However, the McCoys could not have been separated until the era of modern surgery. Dr. Templeton feels that current medical techniques could have separated and reconstructed them successfully, but they may have experienced other medical problems as a consequence.

### Fun for Multiples and Their Familes



**Annual Multiples Family Day at Kings Dominion** Amusement Park in Virginia.

The Multiple Births Foundation of North America invites you and your family and friends to join the fun on July 25, 1998 as multiples from across the Mid-Atlantic states come together to celebrate their unique status as twins, triplets and more. This year's event offers a special "kids deal." Admission for children between 3 and 12 years old is only \$15.00, and for those aged 13 and up admission will be \$19.00. For more information and to order your tickets, please contact:

Paramount's Kings Dominion **Multiples Family Day** P.O. Box 2000 Doswell, VA 23047 (804) 876-5561

If you would like to learn more about the Bunker Twins we suggest you read: The Two: A Biography, by Irving and Amy Wallace. There is also a wealth of information concerning the Bunker and the McCoy twins at The North Carolina State Archives and The Southern Collection at the University of North Carolina at Chapel Hill. We thank Mr. Wilson Angley, Researcher from the Division of Archives and History at the North Carolina Department of Cultural Resources, and Mr. Nick Graham from the University of North Carolina at Chapel Hill, for helping us with this research.