



Kristi Kirschner, MD, Director
Donnelley Family Disability Ethics Program

From The Director's Desk

We are pleased to have a new issue of *Ethics Matters*. Over the next few issues, you will notice some changes. In particular, in addition to our usual updates regarding our Program activities, we plan to have a special topical focus. For this issue, the theme is “**Differing Bodies.**” Mitch Carr from our Health and Fitness Center shares his perspectives on a fascinating controversy unfolding regarding bilateral amputee and elite athlete, Oscar Pistorius. In essence the debate is about Pistorius’ prosthetics. Do they provide him with an unfair **advantage** over the other elite athletes or do they provide him with a **reasonable accommodation** and allow him to participate in a level playing field? The answer to this question ultimately will decide whether he will be eligible to participate in the Olympics with non-disabled athletes, if he were to otherwise qualify.

The second topic is about conjoined twins, with a book review by our own Teresa Savage, PhD, RN, of the DFDEP. Dr. Savage reviews One of Us, by medical historian Alice Dreger who is a faculty member of the Medical Humanities and Bioethics (cont. next column)

Who Gets To Set the Gold Standard?

Mitch Carr, Director
Fitness, Sports and Recreation
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Growing up many of us dreamed of being an Olympic champion. Some may have dreamed of becoming another Mark Spitz in the backyard swimming pool; still others may have emulated Mary Lou Retton on a balance beam at the local park. While the vast majority of us will never realize this dream, if one is able bodied one can at least say he/she had an opportunity.

Oscar Pistorius has this dream. However, Oscar was born without fibulas and had many other physical problems with his feet. This congenital condition required his legs to be amputated below the knee at the age of 11 months. This has not inhibited Pistorius. The South African track and field sprinter hopes to become the first amputee sprinter to compete in the Olympics at the 2008 Beijing Games. Pistorius uses



Courtesy of Getty Images

prosthetic limbs made of carbon fiber to propel him down the track. While his times do not meet current Olympic qualifying standards for men, the games are still more than year away and his times keep improving (story continued on page 2).

(Director's Desk cont).

Program, NU Feinberg School of Medicine. Dr. Dreger critiques the medical assumptions and treatment approach to conjoinment, drawing upon the lived experience of twins who have lived conjoined, to question the wisdom of separation.

Rebecca Brashler, a member of the DFDEP staff, discusses the changes this year in our consultation and ethics committee policies and programs.

Finally, Geoffrey Ong, a senior at Boston University and a volunteer at

RIC for the past six years, explains how his volunteer experience has had an invaluable impact on his life, and shaped his future career.

In future issues, we will introduce our Disability Ethics Scholars; Dr. Debjani Mukherjee, also a member of the DFDEP staff, will share her experiences from her Fulbright Scholarship year in India; we will inform you of our joint consultation with the Hastings Center which RIC hosted this past summer on end of life care and the use of life sustaining technologies for people with disabilities.



Courtesy of Getty Images

(Pistorius cont.)

Sadly, the International Association of Athletics Federations (I.A.A.F.), the governing body for Track and Field, has recently changed IAFF rule 144.2 prohibiting the use of technological aides. The IAFF explicitly states that they do not ban the use of prosthetic limbs, but they classify Pistorius' limbs as technological aides, not as prosthetic limbs. The International Olympic Committee (IOC) does not make the rules and regulations for each sport; they only advise. The I.A.A.F. has recently urged Pistorius to concentrate on the Paralympic games which are designed for disabled athletes. They are concerned that his "technological aides" will affect the purity of the sport by giving Pistorius an unfair advantage over other athletes. Other officials are concerned that he may topple over interfering with the other runners.

The I.A.A.F., in a landmark decision, announced on July 26, 2007 that they will carry out further biomechanical research on Pistorius. This decision was made after a July event in Rome in which Pistorius was filmed with high-definition cameras versus the rest of the able-bodied field. The research began in October 2007 and will be carried out by one of the world's leading independent experts in athletic biomechanics, Professor Peter Bruggemann from the Institute of Biomechanics at the German Sport University of Cologne. Limited research currently shows that a human leg actually returns three times as much energy absorbed in each stride as compared to a prosthetic limb, which would clearly not give any advantage to

the able bodied runner. The I.A.A.F. suggests that Pistorius' limbs increase his stride length and that this gives an additional advantage, and that the speed in which the normal leg travels through air is slower than the artificial legs. Pistorius maintains that his stride length is well within the determined range for his height. In fact, he faces specific disadvantages because his power output is decreased due to range of motion limitations in his knee, and he also has to deal with rotational forces with the prosthetics that could slow him during a sprint.

Pistorius may not win his fight. He may ultimately be prevented from competing. He has, however, started an intriguing debate for the sporting world that will not go away. The questions are simply who can compete and who cannot? Are his limbs prosthetics or technological aids? Do his prosthetics provide him an unfair advantage or simply level the playing field? If he is able to compete with an appropriate accommodation that does not give him an unfair advantage, shouldn't he be allowed to compete based on non-discrimination principles?

The inclusion of disabled athletes into able-bodied sports has been raging for years. When I was in junior high school I remember reading in *Sports Illustrated* about this dynamic pitcher from the University of Michigan who had one arm. He pitched by using his stump to hold his glove and then he would transfer his glove over to his pitching hand to field. Because his arm was considered a liability, Jim Abbott was given a slim chance to make the major leagues. He proved his critics wrong by leading the 1988 U. S. Olympic baseball team to a gold medal. He spent 10 years in the major leagues, winning 87 games, and on September 4, 1993 while pitching for the New York Yankees, he pitched a No-Hitter. Jim Abbott was given no

special consideration. He was simply given the opportunity, faced the challenges, and adapted. This is what all disabled athletes want, a chance to compete.

I believe it is time for the national governing bodies of all sports at any level to take a serious look at this issue. The I.A.A.F. needs to take the time and diligently research athletes with similar proportions to Pistorius and similar hip and knee torque outputs to Pistorius and see if the device does offer an advantage. If it does, then prosthetic manufacturers can work on modifications to level the playing field; if it does not, then he should be given the same opportunity to participate and prove if his performance is worthy of Olympic competition. Anything less than this would send a poor message to our youth, that if you have a disability, then you are different and your dreams of being an Olympian will be prevented from becoming a reality.



Mitch Carr

ONE OF US

conjoined
twins
and the
future
of
normal



ALICE DOMURAT DREGER

Upcoming Events For RIC Staff

Film Series:

Tues. Jan 29th: **Burden of Knowledge**

Fri. Feb. 29th: **Lieba Perla**

Mon. Mar. 31st: **The Key of G**

For information about times and locations please contact Carmen Cicchetti at 8-1119 or ccicchetti@ric.org

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Book Review: *One of Us*

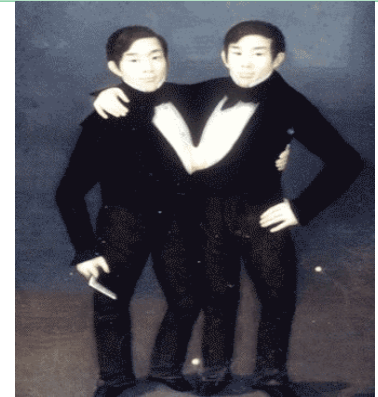
Written by Alice Dreger (Harvard University Press, 2004)

Teresa Savage, PhD, RN

Donnelley Family Disability Ethics Program

Recently, a child in India who was born with four arms and four legs underwent 27 hours of surgery to remove the extra limbs, receive a kidney from her "parasitic twin" and have her spine straightened. Newspaper reports said that rural villagers revered the little girl, named Lakshimi, as an incarnation of the four-armed goddess for which she was named. Like moths to a flame, we are drawn to look and be fascinated by the difference. Alice Dreger's book, *One of Us*, invites us to look deeply into the experience of the bodily difference of conjoined twins. She challenges us to abandon our pre-conceived assumptions about the intolerability of that existence and the paternalistic medical rescuing through separation surgery. Beginning with the story of Chang and Eng Bunker, the first "Siamese twins", Dreger reveals their long, productive, and individual lives as conjoined twins. It is the first of many stories she shares in this fascinating and informative book on conjoined twins.

Consistent with her work on intersex, Dreger does not accept that bodily differences must be "fixed". After a brief tutorial on the types of conjoinment, she begins by tackling the issue of individuality. Parents recognize the unique personalities of each twin. Over time the twins negotiate their day-to-day living, and as adults, they may pursue separate hobbies and occupations, dating and having intimate relationships. While one twin is having sex, the other is quiet and "mentally distant". Chang and Eng each had a wife, 10 and 12 children respectively, and separate homes. Dreger reports that most twins do not wish to be separated. There is a cultural



A painting of Cheng and Eng Bunker, circa 1836

perception in the U. S. that Americans equate independence with being one individual; interdependence is equated with weakness. Thus to be independent individuals, twins must be separated. Many conjoined twins, however, view themselves as two individuals. In numerous examples, Dreger relates stories of conjoined twins who thrive. She also relates stories of those who were separated so they would be "more normal" only to be "deformed" by the separation.

One set of twins, Katie and Eilish, were born in Ireland in 1988. Joined at the shoulder to the pelvis, they had two hearts and two sets of lungs, but shared their lower gastrointestinal and reproductive system. The parents wanted to "normalize" their appearance. The separation would involve splitting the organs so one twin would get the bladder and urethra, the other would get the rectum and anus. Each would get half of the uterus, vagina, and external genitalia. Each would get one leg. They would go from being a healthy set of conjoined twins to two markedly disabled girls. At nearly 4 years of age, the twins underwent surgical separation. Katie died four days (story continued on page 4).

(*One of Us*, cont.)

after the surgery from cardiac insufficiency that was not apparent on prior testing. Eilish survived and, despite her deep distress at losing her twin, named her prosthetic leg Katie.

Dreger raises and offers discussion of these questions for parents considering separation surgery:

1) "What, exactly, are the goals of these surgeries? And are those goals likely to be achieved? (p. 60)

2) What do people do who have grown up "uncorrected" say about living with the condition? Have some of them chosen normalization surgery

for themselves, or expressed a wish that their parents had chosen it for them when they were infants? (p. 67)

3) What are the minimum negative effects that will result from the surgery? And what are the maximum possible negative effects? (p. 68)

4) Are childhood surgeries the most appropriate or effective way to deal with the psychosocial concerns? (p. 70)

5) Could the normalization procedure be postponed until the child is old enough to make the decision? (p. 73)

6) In what way might the

interests of the adults unduly influence their decisions? (p. 75)

7) In what other ways are the adults' choices unduly constrained? (p. 76)

8) Are the parents fully informed when making decisions? (p. 80)

9) Is it ethical to choose when the surgery will certainly undo the body the child was born with?" (p.81)

In story after story, Dreger argues that the desire for normalization is misplaced. In the spectrum of physical variation, perhaps conjoinment should be embraced.



Rebecca Brashler

In June of 2006, the Medical Staff Committee voted to formally establish a hospital ethics committee. A steering committee was formed to identify the desired composition, structure and function of the committee. The Steering committee became the Core (c) members, who serve open, non-rotating terms. The rest of the committee members serve either two or three-year terms. The members are: Dr. Kristi Kirschner (c), Chairperson, Dr. Teresa Savage (c), Vice-Chair, Teresa Alvarez, Nancy Ardell, Rebecca Brashler (c), Dr. Leora Cherney, Carmen Cicchetti (c), Diane Dudas, Dr. Aaron Gilbert (c), Anita Halvorsen (c), Dr. Norman Harden, Ed Hitchcock, Leslie Jellinek, Rev. David Kylo (c), Anaida Lopez, Dr. Debjani Mukherjee(c),

The RIC Hospital Ethics Committee

Rebecca Brashler, LCSW

Clinical Educator

Donnelley Family Disability Ethics Program

Dr. Sue Mukherjee, Joan Opas, Arlynn Ostlund (c), Leah Pentz (c), Judy Panko Reis, Dr. Scott Roberts, Dali Smith (community member), Sally Taylor, Dr. Santiago Toledo (c), Dr. Rich Trezona, Dr. Katie White, and Dr. Felise Zollman. Each year the most senior medical resident leaves the committee and a first year resident joins the committee for the duration of the residency.

The Hospital Ethics Committee By-Laws. The Hospital Ethics Committee shall consist of at least three (3) members of the Combined Medical Staff, at least one (1) of whom shall be a member of the Attending Medical Staff, one of whom will serve as Chairperson. Other members shall include professional staff of the RIC ethics program, a Resident Physician, a nurse in clinical practice, an allied health professional in clinical practice, and a care manager.

Additional members may be added at the discretion of the Chairperson.

The Hospital Ethics Committee shall:

- A. Promote ethical practices in the care of patients and in the business practices of the hospital;
- B. Serve as a forum for the discussion of specific or general ethical issues that may be identified by hospital staff, patients, or members of the Combined Medical Staff;
- C. Develop and present educational programs for members of the Combined Medical Staff, clinical staff, and administrative staff.
- D. Serve as a subcommittee of the Medical Care Committee and shall report to the Medical Care

(story continued on page 5).

(HEC, cont.)

Committee at least once per year.

The Hospital Ethics Committee shall meet at least quarterly.

The HEC began meeting monthly in September 2006. Topics that the committee has addressed include the results of the system-wide ethics survey from March 2005, overnight visitation policy, the VIP patient and differential services, and domestic violence and the media. The members are also informed

of the nature of the ethics consultations that are requested.

At RIC, there are a number of mechanisms to address ethical issues. Clinicians and staff are encouraged to discuss difficult clinical and institutional issues within their treatment teams and units. If a situation warrants further exploration, any member of the team including patients and family members, may contact the Donnelly Family Disability Ethics Program at 312-238-1312. Ethical issues

that involve a specific patient will be referred for consultation. The consultation may range from a private informal discussion that includes only the referring party to a formal team/family meeting designed to collect information, mediate conflict and/or clarify treatment options. Ethical concerns that involve rehabilitation care at RIC but do not arise around the care of a specific patient will be referred to the Hospital Ethics Committee.

What RIC Has Taught Me: Reflections of a Volunteer

I first found myself in the office of Aimee Look, supervisor of volunteer resources at the RIC while I was a sophomore at the Latin School of Chicago. The Rehabilitation Institute was recommended to me by my high school counselor who knew of its vibrant volunteer program and my pre-medical plans for college. It was an invaluable opportunity for a teenager who had an interest in the medical profession and wanted to get his feet wet. Eager to work directly with patients, I decided the best way to accomplish this would be to assist with the Sunday afternoon recreational activities.

My first experiences as a volunteer were of mixed feelings. There was a certain amount of trepidation as I experienced first-hand the limitations and at times powerlessness of volunteers, but at the same time the positive effects of the recreational activities. Although the purpose was to be proactive, the challenging aspect was to decide when to engage the patients in activities while mindful of both their own and their families' privacy and needs. As the Rehabilitation Institute strives to improve the quality of life of patients with disabilities, it was important for volunteers to keep in mind

Geoffrey Ong

RIC Volunteer since 2001

not to get beyond their boundaries in helping the patients, which would unintentionally underscore their disabilities and hinder their independence.

There are some in society who may have a rather negative perception of people with disabilities due to a few unpleasant encounters or negative stereotypes. I have found this outlook to be misguided. I grew up in one of the few lakefront high-rise residential buildings with Braille signs in the elevators. The blind residents who live there all lead independent, well-adjusted lives. They work, travel, serve on the condo board and clean up after walking their seeing-eye-dogs — a chore that quite a few sighted persons often fail to do. Those with a lack of understanding have overlooked or taken for granted the intricate process in which people with disabilities have to adapt to daily life. The treatment process which I have witnessed at RIC has filled me with respect for those who work there



Geoffrey Ong

and has given me a deep level of respect for people with disabilities. It is not pity they are after, but rather a thoughtful understanding of how they must adapt their lifestyles in the face of their circumstances and not to be relegated to second-class citizenship.

I found my first year of volunteering to be a truly invaluable experience which few of my high school peers had encountered. It provided me with a more mature understanding of physical disabilities, and an overall experience which I brought into my pre-medical studies. However, there remains something to be said for planning too far ahead. I realized during my freshman year in college that the medical profession (story continued on p. 6)



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were when I arrived at RIC to help coordinate an activity and found out that the “regulars” had gone home after they had successfully completed their treatment.

It has been six years since I first volunteered at the RIC, and I can honestly say that my experiences have been nothing short of enriching. A high school community service requirement that was borne out of an interest in medicine has indelibly turned into something much more valuable.

(volunteering cont.)

was not the best fit for me. As I switched my academic track to pre-law, the positive experience and the level of care at the RIC helped me to decide on my chosen area of specialty, health law and policy. I continue to volunteer at the Institute as it reinforces my knowledge from public policy courses in college. Last summer, my volunteer work with the Human Resources Department allowed me to gain general office experience, while observing the inner-workings of the support staff that makes it happen. This past summer I volunteered to work for the Donnelley Family Disability Ethics Program, and while I was unable to explore in depth the ethical issues that confront the medical field regarding people with disabilities, the exposure to the staff, the publications and the work environment has stimulated further interest in medical ethics and disability and should continue when I enter the health

law field. The experience of volunteering at the RIC is similar to my recent internship with a London law firm.

This past semester, I had the opportunity to intern at a department of a British law firm which specialized in corporate legal advice to charities and not-for-profit organizations in the U.K. I found the intentions of the lawyers I worked for to be refreshing and noble. I was in the company of individuals who were trained in the commercial and corporate legal sectors but who had turned down the high-salaried positions in favor of becoming less well paid lawyers whose client base benefited society. I believe that their goals are no different from mine or other volunteers at the RIC who look beyond monetary gain and only wish to improve lives. Some of the most rewarding moments

Ethics Resources for RIC Staff

There are a variety of ethics resources available for all members of the RIC community. Currently located on the thirteenth floor in Room 1374, the Donnelley Family Disability Ethics Program houses a library, periodical section, and VHS/DVD collection all geared to enabling members of the RIC community to familiarize and keep themselves current on ethical issues surrounding disability.

Library. The Ethics Library now houses 723 volumes, and new books are being added constantly. The library incorporates a broad spectrum including, but not limited to, works on biomedical ethics, disability rights, and narratives of those living with a disability. Staff may check out three items (three books, three videos/DVDs, or a combination of the two)

for two weeks, and may renew items for an additional two weeks. We invite you to come browse and to utilize our library as a quiet place to read and reflect.

Periodicals. We currently subscribe to twenty-four periodicals. Among these are *Archives of Physical Medicine and Rehabilitation*, *Journal of Disability Policy Studies*, *The Journal of Clinical Ethics*, *The Hastings Center Report*, *Disability and Society*, and *the American Journal of Physical Medicine and Rehabilitation*. Periodicals may not be removed from the library.

Film Library. Our film library has 202 videos/DVDs on a wide variety of ethical issues regarding disability. These may be checked out for two weeks, and renewed for an additional two weeks.

Film Series. Once each month, we show a film from our library collection. Although the film is always shown at noon, the day varies to enable a variety of staff to attend.

Educational Seminars. Ethics Program Staff routinely present educational seminars on ethical issues which are typically requested by RIC staff. The schedule for such seminars as well as our film series is listed on page 2.

Ethics Scholars Program. Staff teach a one-year program open to all members of the RIC community. The goal is to provide in-depth training and professional development in ethics.

Ethics Consultations. Ethics consultations are available upon request by calling 312-238-1119.