CH is a world leader in heart disease treatment for children & non-related bone marrow transplants.

See enclosed info.

Evan - Video I think
HRC would want to do.
Draft also attached.

Pam

CJRW outmarketing

Cranford Johnson Robinson Woods
FAX TRANSMITTAL SHEET

Date: 8/10/99

To: Nancy Hoarneich - Pam Cicotti

From: Skip Rutherford

Number of pages sent including this sheet: 3

If you have any problems receiving this facsimile, please contact Dianne Kelly at (501) 975-7266.

Thank you.

Capitol Center / 303 West Capitol Avenue / Little Rock, Arkansas 72201-3593
FAX: (501) 975-6045 or (501) 975-6085

Comments:

The Children's Hospital of Wisconsin will pay for the video - Larry Woodard used to be at Arkansas Children's - WORT to church with HMC. I hope HMC can do this. Call me with any questions - Thanks Skip

Draft script attached

Cranford Johnson Robinson Woods
Advertising Public Relations OutMarketing
303 West Capitol Avenue Little Rock Arkansas 72201
501-975-6251 Fax 501-975-6[illegible]

TO: Laura Schiller and Ch.Woodshapiro.com

Children's Health System™

CMN Champions — Children's Miracle Network

Children's Hospital Foundation
M.S. 3050 • P.O. Box 1997 • Milwaukee, WI 53201
(414) 266-6118 • (888) 543-7233 • fax (414) 266-6139

August 5, 1999

Larry C. Woodard, FAHP, CFRE
Executive Vice President

Mr. Frank Cox
Cranford Johnson Robinson Woods
Capitol Center
303 West Capitol Avenue
Little Rock, AR 72201-3593

Dear Frank:

It was great to talk to you the other day, and I deeply appreciate your assistance and Skip's in helping us with our request to obtain a video from Hillary that we can use for our November 19, 1999 gala evening. As I mentioned, Bill Cosby will be the main speaker for this black-tie, invitation-only event. We will have approximately 1,000 people in attendance.

The focus of the evening is a "celebration of successes," and the theme will be "Through The Eyes of a Child." It will not be a fund raising event in itself. Instead, the evening will highlight our world-class research initiatives as well as clinical and outreach programs...celebrate the 10th anniversary of the move of Children's Hospital of Wisconsin to its present location...and the announcement of some very major gifts.

We also will be utilizing a video that will highlight the current strengths and "firsts" of Children's Hospital of Wisconsin as well as our future direction, with the main focus on our desire to establish ourselves as one of the nation's leaders in pediatric research and the important role it will play for children throughout this country. Children will play various roles throughout the evening, such as introducing the video, entertainment, etc. The entire evening will be very uplifting, child-focused, and one that will leave the audience feeling proud to be a part of our present as well as our future.

With Hillary's long-time commitment to children everywhere and her friendship with Jon Vice, the president of the Children's Health System (the parent of Children's Hospital of Wisconsin) we felt there could be no finer spokesperson to address the evening's audience in the way we have outlined in the proposed script. I'll be more than happy to discuss any changes to the script you or Skip might propose in order to make sure Hillary is comfortable with everything. We are extremely hopeful this request can be brought about, because it will surely be one of the highlights of the evening for all present, and I know will mean a great deal to everyone to hear the words of this country's first lady thanking them for their day-to-day efforts on behalf of the children.

If you or Skip have any questions whatsoever, please don't hesitate to call me at (414) 266-6118. Talk to you soon.

Sincerely,

Larry C. Woodard
Executive Vice President
LCW/ck

Script for Hillary Clinton
Children's Hospital of Wisconsin Celebration of Children

During this gala celebration of children, I'd like to commend the staff of Children's Hospital of Wisconsin for the dedication, skill and commitment each person brings to the cause of helping children get well and stay well.

I'd also like to offer my congratulations to you, Jon, on your 20 years as president of such a wonderful institution. Over the years, I've appreciated your consul here at the White House. As you know, the health and well-being of children are issues very close to my own heart, and I'm thankful for the experience and insights you have shared that not only have benefited Wisconsin's children, but those from across our nation.

And, I'm sure, the families of Wisconsin who rely on Children's Hospital and the state-of-the-art medical care it provides are just as thankful. Initiatives like your cardiovascular surgery program, craniofacial center, bone marrow transplant program, and the Jane B. Pettit Pain Management Center certainly are among the finest in the nation. Your "Comfort Zone" philosophy is a model for care that will serve as an example for all pediatric medical centers. That kind of compassionate care has long been a hallmark of Children's Hospital of Wisconsin, and something all of you should be very proud of.

Just as important are those programs that prevent illness and injury in children; programs like those of the Health Education Center that teach children the wonder of their bodies; violence and injury prevention intiatives; the Child Protection Center; and a host of other community health and education initiatives.

I expect in the coming years that we'll be hearing more across the country about the state-of-the-art research programs that have become priorities for Children's Hospital. The genetic approach shared by your Birth Defects Center and the Max McGee National Research Center for Juvenile Diabetes will take the best aspects of this newest branch of science and fundamentally change how we diagnose, treat, and even cure diabetes and cardiac and neurological birth defects. These research programs, as well as others underway at Children's Hospital, will help the scientific community make giant steps toward the day when these illnesses are no longer a concern for families.

Over the years, Children's Hospital of Wisconsin has grown and matured to become one of the nation's crown-jewel pediatric medical centers. I congratulate all of you on this wonderful occasion and send you my warmest wishes for your continued success.

- OD
Videos

FIRST LADY HILLARY RODHAM CLINTON
VIDEOTAPED REMARKS FOR CHILDREN'S MERCY HOSPITAL
CENTENNIAL DINNER
FEBRUARY 6, 1997

Good Evening. I very much wanted to join you at this celebration of Children's Mercy Hospital's 100th birthday, and I'm sorry that other events have kept me from coming. I was looking forward to another trip to Kansas City, to visiting one of our country's finest pediatric hospitals, and to catching with my old friend from Arkansas, Rand O'Donnell.

But I am delighted to be able to send my best wishes to all of you on this special night. As you celebrate a century of service to the children and families of Kansas City, you have a unique opportunity to reflect on the rich experiences of the past and on the lessons that will guide you in the future. If your founding doctors, Katherine Berry Richardson and Alice Berry Graham, were to come back today, they might not recognize the state-of-art complex that has grown from their original five-bed hospital on Highland Avenue. But they would have no trouble seeing that their hospital's fundamental commitments to excellence, to education, and to serving all children in need of medical care are still thriving. And those are the commitments we will all need to carry into the new century.

For one hundred years, the doctors, nurses and patrons of this hospital have recognized that children are our country's most precious resource. To all of you at Children's Mercy, each child who comes through your doors doesn't represent a race, a religion, or an economic class, he or she represents our hope for the future. That is why you have dedicated your hearts, minds, and hands to making sure every patient has the chance to fulfill his or her God-given potential. Your cutting edge research into childhood disease, your use of the most innovative treatments, and your boundless compassion have helped heal the bodies and spirits of thousands of children and offered comfort and hope to their families.

You have also helped your patients grow. The classroom which has been a part of Children's Mercy since 1917 represents a belief that illness need not stunt a child's intellectual and emotional growth. A love of learning is a fundamental part of a healthy childhood. And that begins with a love of reading. As many of you know, new research has shown that reading to young children is vital to their neurological, intellectual, and emotional development. Last month, I announced, along with representatives of the American Academy of Pediatrics, a national campaign to encourage doctors to prescribe daily reading to children and their parents. I hope all of you will support us in this effort.

I congratulate you on a magnificent century. I have no doubt that all Americans will continue to look to the leadership of Children's Mercy Hospital in years to come. Have a wonderful evening.

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Children's Hospital of Wisconsin

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children first

Children First

Nothing is more heart-warming than the sound of a child's laughter. And no other commodity is more precious to our nation's future than the well-being of America's children.

Children First is a campaign designed to raise awareness of the challenges facing children today. In Wisconsin, two ABC stations and Children's Hospital of Wisconsin are working together to encourage the public to take action on behalf of children.

Launched in January of 1994, Children First is a joint ABC network-affiliate campaign that uses today's most powerful communication medium – television – to deliver positive, action-oriented public service messages about mentoring, family, safety and health, self-esteem and education to adults and youth.

We hope to help children overcome the obstacles that inhibit their growth and learning potential by stressing what each adult, parent, neighbor, or member of the community, business or civic organization can do. The message of Children First is: There is something each of us can do to help children.

Children First Partners:

In Milwaukee

Jewel-Osco

Children's Hospital of Wisconsin

WISN TV

In Green Bay

Children's Hospital of Wisconsin

abc 2 WBAY-TV

Report any problems or comments about this web site to Webmaster@chw.org

- OLD VIDEO

FIRST LADY HILLARY RODHAM CLINTON
CHILDREN'S CIRCLE OF CARE LEADERSHIP CONFERENCE
MAY 5, 1998

Thank you, Mary, for that introduction. I only wish I could be there in person for this Children's Circle of Care Leadership Conference. As some of you may know, I attended this conference two years ago when it was held at the National Institutes of Health in Bethesda, and I'm proud to have served as your founding honorary chair.

Having worked almost fifteen years as a volunteer and Trustee at Arkansas Children's Hospital, I know first hand the extraordinary role that these hospitals play in the lives and health of our nation's children. In fact, one of the pleasures I've had as First Lady has been the opportunity to visit so many of your children's hospitals across America where I have seen your commitments in action. And I know that the same quality of work is being carried out in Canada's hospitals as well.

But it is as a mother that I most appreciate the work that our children's hospitals do and the generosity that lets them keep on doing it. It has only been through your support -- and through the support of people like yourselves -- that so many hospitals have been able to advance their shared mission of excellence in pediatric patient care, research, teaching, and advocacy.

I want to commend all of you on the work that you've accomplished since your first Leadership conference here two years ago. And I wish you luck as you continue to help the children's hospitals of the United States and Canada fulfill their vital role. I hope you have a wonderful conference.

PR info on hospital

BMT Web copy

The Children's Hospital of Wisconsin bone marrow transplant program is known internationally for its success in transplanting unrelated and partially matched donors in the treatment of childhood cancer and rare blood diseases. See story

The hospital operates one of the largest and most experienced pediatric bone marrow transplant programs in the US. Pediatric oncologists working in the program were among the first practitioners of a breakthrough transplant technique, now widely used, called T-cell depletion.

Click here for more about T-cells.

These physicians are on the faculty of the Medical College of Wisconsin.

Success requires the coordinated effort of specialist doctors, nurse practitioners, oncology nurses, laboratory scientists, dietitians, physical therapists, occupational therapists, psychologists, social workers and Child Life specialists.

The overall strength of this team has enabled Children's Hospital's bone marrow transplant survival rate to exceed the national average, and for some diseases survival rates are much better than the national averages.

The program also benefits from being located at a major pediatric medical center, with one of the most advanced pediatric intensive care units in the Midwest, guaranteeing immediate access to the full range of specialists and subspecialists. That is important because many patients need critical care services at one point or another in their treatment.

Inpatients stay in the Hematology/Oncology Transplant (HOT) unit, a bright, modern, fully equipped, 24-bed facility on fifth floor of the hospital's east tower. The HOT unit features six exercise bikes and its own play room, offering a wide selection of toys and games. Every effort is

made to bring some semblance of normalcy to the hospital experience during the typical five to six weeks of inpatient treatment.

Before and after treatment, children are seen in the Hematology/Oncology Clinic on second floor.

About the procedure

To kill some forms of cancer, radiation and chemotherapy must be used so aggressively bone marrow also is destroyed. In leukemia, the cancer is in the bone marrow, and the marrow must be destroyed to halt the disease.

Bone marrow houses stem cells, from which the body manufactures blood and infection-fighting antigens. Bone marrow transplantation is a way to reinstall these essential systems after high-dose anticancer therapy.

Sometimes people may have the misconception that bone marrow transplantation involves surgery. Actually, it is an intravenous infusion procedure, similar to the way liquid medications and nutrients are "dripped" into the bloodstream. Held in liquid suspension, the donor cells migrate to the central bones and starts rebuilding blood supply and immune system.

Autologous transplants

Bone marrow transplantation begins with selecting the best available donor. In some cases that might be the patient. This is called autologous transplant. Donor marrow or stem cells are harvested from the patient and frozen at ultra-low temperature. After chemotherapy and/or radiation treatment,the donor cells are unthawed and reinfused into the patient.

Harvesting bone marrow, usually from the pelvic bones, takes place with the patient under general anesthesia. Stem cells are obtained by processing the patient's blood in the laboratory. The blood is drawn from a peripheral part of the body (distant from the heart) over the course of several

days, after the patient first is given a drug to promote stem cell growth.

Autologous bone marrow transplants are, by definition, genetically identical to the host. Therefore, T-cell depletion is unnecessary.

The disadvantage to autologous transplants is that the seeds of disease may lie within the donor material itself, and to use it would risk restarting the cycle of illness. Or, harvesting enough donor cells for reinfusion might be impossible.

Allogenic transplants

The alternative is **allogenic** transplantation, in which the donor cells come from another person. Except in the case of identical twins, no two people are a perfect genetic match. But for a bone marrow transplant to be successful, a match is needed only in certain sections of a genetic segment called the HLA complex.

The HLA (human leukocyte antigen) complex determines the makeup of each person's immune system. A person's immunological signature, in effect, can be defined in terms of clusters of HLA genes. Different people are born with different clusters, each combination defined as an HLA type and identifiable by blood test.

HLA type is handed down from parents to children. Children inherit half of their HLA type from each parent. Therefore, according to the laws of genetics, siblings have a one-in-four chance of being wholly HLA-matched.

Because of the reduced risk of rejection, wholly matched donors always are the first choice. There may not always be one, though.

Instead, a partially matched donor is used, with T-cell depletion being performed on the donor cells. In some cases, highly specialized T-cells may be put back into the donor material in order to combat specific viruses to which the patient previously was exposed. These include

Cytomegalovirus and Epstein-Barr virus.

Donor cells are harvested by drawing bone marrow or extracting stem cells from peripheral blood, the same as in an autologous transplant. Usually, though, the materials are not stored, but are obtained close to the time of transplant and used immediately. One exception is cord blood – stem cell-rich umbilical cord blood which was banked for future needs. Stem cell transplants derived from cord blood occasionally are performed, but only on smaller children, because of the smaller amount of donor cells available.

With a suitable donor identified, the patient undergoes appropriate chemotherapy and/or radiation therapy, lasting as long as a week. This phase of treatment is very stressful for families because patients emerge from it severely weakened, nauseated, unable to eat and suffering other side effects, including hair loss.

Immediately after anticancer treatment ends, patients receive their bone marrow transplant. Weeks of arduous and post-transplant treatment begin, supervised by a team of specialty doctors, nurses and therapists.

About our treatment team

Health professionals in the Children's Hospital of Wisconsin bone marrow transplant program bring a variety of strengths to the table. Years of experience have taught that successful outcomes hinge on a highly collaborative team effort. It truly is a full-service approach to addressing the needs of both patient and family.

• **Doctors:** In charge of medical treatment are pediatric oncologists on the full-time faculty of the Medical College of Wisconsin. Their position with the college means they are actively engaged in research and versed in the latest developments. They rely heavily on each other for advice and input in making difficult treatment decisions and regularly consult with colleagues from around the

country and the world. Indicative of the international respect they command, they have drawn patients from as far away as the Soviet Union.

• **Nurse practitioner:** Patient care is coordinated by a pediatric oncology nurse practitioner who works closely with the patient and family to explain tests and procedures and the reasons for them. The nurse practitioner addresses any concerns that may arise, helps the family solve personal problems and acts as interface between doctors and nurses. Other duties include conducting physical exams, writing prescriptions, creating a treatment time line and helping with discharge planning.

• **Nurses:** Patient care is delivered by pediatric oncology nurses assigned to the HOT unit. Each patient is assigned a primary nurse who follows the patient throughout his or her hospital stay and subsequent visits. This system lends some much-needed continuity to a situation in which patients and parents feel helpless and stressed. The sophistication of care on the unit approaches an intensive care level, and nurses must be competent in advanced procedures. They also have to be a special kind of person -- strong but compassionate, cognizant of the need for children to play and learn and find joy in life, no matter how desperate their circumstances.

• **Physical/occupational therapists:** Children capable of walking each are assigned a physical therapist who begins working with them the day after transplant to help them regain strength and flexibility. This has been shown to cut recovery time in half. Every patient receives at least half an hour of physical therapy a day. Coordinating with the nurses, the physical therapist tries to get children on their feet and engaged in physical play. Rebuilding endurance takes time, because patients emerge from therapy very weak and debilitated. The same goes for babies. Because their greatest need is to develop upper body strength and coordination, each is assigned an occupational therapist.

• **Dietitian:** Because good nutrition is so important to rehabilitation, each patient is assigned a dietitian whose top priority is to get the child eating again as soon as possible. Successful weaning from tube feeding to solid food takes skill and experience, because nothing tastes good to children undergoing transplant. Their mouths hurt, their tummies hurt, and for a long time after transplant they may have difficulty keeping meals down. Getting them to enjoy eating again isn't easy. To meet this challenge, the dietitian has to work closely with the doctors, nurses and therapists. In an effort to make food more appealing, the hospital offers room-service-style meals, in which children can order anything on the menu.

Click here for more about Room Service

• **Psychologist:** Mental health support is offered to families by a child psychologist who helps devise coping strategies both for patient and parent, because parents set an example, and how well they cope often affects how well their children cope. Treating anxiety and depression is a major concern, but the psychologist also deals with all the collateral issues faced by families in crisis. The psychologist works as part of a mental health team comprised of everyone involved in treatment. The team meets weekly to discuss patients' progress. For parents of children with cancer, the hospital offers a support group.

Child Life: Children undergoing treatment receive day-to-day emotional sustenance from the HOT unit Child Life specialist. Trained to relate to children on their own level, Child Life specialistsis are playmate, best pal, cheerleader, therapist and shoulder to cry on, all in one. Besides working with kids individually, they organize parties and group activities. They empower the children by making them feel part of a community. They try to build self-esteem and a positive self-image. Hand-in-hand with that, they teach patients self-hypnosis and relaxation techniques for relieving anxiety. They always are there when a child feels lonesome, just needs someone to talk to,

or get goofy with. It sound so simple, but means so much.

• **Social Worker:** In recognition of the strain bone marrow transplants cause for families, each one is assigned a social worker who helps people cope with the details of day-to-day living. When families relocate to Milwaukee for the duration of treatment, the social worker helps them find housing, transportation, schools and day care. When tensions run high between family members, the social worker mediates. When families run into money problems, the social worker hooks them up with charitable and government financial resources, such as the Dan Jansen Foundation. The social worker also sees to it that patients continue in school (which the hospital facilitates by having teachers from the local school district on site). Conveying this expectation is important because learning is something kids can feel proud of and is a way for them to feel normal. Most bone marrow transplant patients at Children's Hospital manage to keep up in school.

Scientific know-how, great depth of experience, compassionate care and an unusually comprehensive team approach distinguish the Children's Hospital of Wisconsin bone marrow transplant program from other programs. Inquiries are welcome from health professionals, patients and families.

More about T-cells

T-cells (T lymphocytes) form the building blocks of the human immune system. Their job is to battle invading organisms. Removing them from donor marrow thus lessens the likelihood it will recognize host cells as foreign and attack, giving time for the graft to take root and permitting use of donors who are only partially matched genetically.

The pool of possible donors now can include partially matched relatives and unrelated

persons. It is now common for birth parents to serve as donors, even though they are only half-matched genetically with their children.

This means new hope not just for cancer patients, but victims of nonmalignant blood diseases and disorders treatable only through bone marrow transplant. Examples include aplastic anemia, immune deficiencies and sickle cell anemia. Malignancies commonly treated with bone marrow transplant include acute and chronic leukemia, lymphoma, Hodgkin's disease, multiple myeloma and solid tumors such as breast cancer and ovarian cancer.

-30-

Children's Hospital of Wisconsin ™

Children's Hospital of Wisconsin exceeds standards of excellence for congenital heart surgery

In 1997, surgeons at Children's Hospital performed 603 heart operations – 280 open and 323 closed – with a mortality rate of 1.4%. The accepted norm for these procedures is a mortality rate of 3% to 7.1%. Below, are statistics for the period from 1994 through 1997.

Heart surgery at Children's Hospital of Wisconsin

Year	Total	< age 2	Open	Closed	Mortality
1997	603	350	280 (4) 1.4%	323 (0) 0%	0.7%
1996	559	330	277(10)3.6%	282 (3) 1.1%	2.3%
1995	482	302	226 (15) 6.6%	256 (2) 0.8%	3.5%
1994	414	273	211 (4) 6.6%	203 (2) 1%	3.9%

Who is at risk following the Norwood procedure?

Identification of patients at risk for low systemic oxygen delivery following the Norwood procedure for hypoplastic left heart syndrome.

James S. Tweddell, MD; George M. Hoffman, MD; Raymond Fedderly, MD; John M. Kampine, Jr., MD; Nancy S. Ghanayem, MD, Stuart Berger, MD and S. Bert Litwin, MD. Departments of Surgery (cardiothoracic surgery), Anesthesia, Pediatrics (cardiology and critical care), Medical College of Wisconsin, Children's Hospital of Wisconsin, Milwaukee, Wis.

Early identification of low systemic oxygen delivery in patients with hypoplastic left heart syndrome (HLHS) following the Norwood procedure should improve outcome.

Methods: In this prospective study following the Norwood procedure (from 6/96 to 2/98), superior vena cava saturation (SvO_2) and arteriovenous oxygen content difference (ΔAVO_2) were recorded hourly for the first 48 hours in 22 consecutive patients.

Age, preoperative support, shunt size and anatomic subtype (aortic atresia v. antegrade aortic flow) were evaluated using multiple logistic regression to determine their impact on early postoperative systemic oxygen delivery. Satisfactory oxygen delivery was defined as an $\Delta AVO_2 \leq 5$ vol% and $SvO_2 \geq 50\%$.

Results: Thirty-day survival was 100%. There was one hospital death and hospital survival of 95% (21/22). Risk factors for decreased systemic oxygen delivery are summarized in the table below.

Conclusion: Aortic atresia, older age, larger shunt size and preoperative suport are previously identified mortality risk factors. These same factors were predictive of decreased systemic oxygen delivery, which could be effectively managed using continuous SvO_2 monitoring.

Age	Risk for $SvO_2 \leq 50\%$		Risk for $\Delta AVO_2 \geq 50\%$	
	p value	odds ratio	p value	odds ratio
<8 days	p<0.001	1.75	p=0.022	1.46
↑ shunt size	p=0.004	1.52	p<0.001	1.96
preop vent	p<0.001	0.24	p=0.35	
preop Ino	p=0.002	1.76	p=0.7	
Ao atresia	p<0.001	1.86	p<0.001	2.13

Children's Hospital of Wisconsin ®

The Heart Center

Children's Hospital of Wisconsin

As recently as 10 years ago, most infants born with **hypoplastic left heart** died. Today, repairing this congenital heart defect accounts for 35 percent of the work we do in The Heart Center at Children's Hospital of Wisconsin. Since July 1996, we have performed 34 **Norwood procedures** to correct this defect, with 32 hospital survivors (a 94 percent survival rate).

In addition, between 1994 and 1998, we performed 51 arterial switch procedures for transposition of the great arteries with a 100 percent survival rate.

Fundamental changes also have taken place in our **cardiac catheterization lab.** It has become routine to **coil occlude** the small or moderate size patent ductus arteriosus (PDA) or other undesirable collateral blood vessels. Done as an outpatient procedure, it obviates the need for surgery. We also have begun using the **Amplatzer device** for large PDAs and plan to soon use it for closure of atrial septal defects, also in the catheterization laboratory.

Balloon dilation of valve obstruction or narrowed arteries now is done routinely during cardiac catheterization in children of all ages. Last year we placed 25 coils, performed 17 balloon valvotomies and 22 balloon angioplasties of either narrow or obstructed pulmonary arteries or recurrent coarctation of the aorta.

Even though the number of complex surgical cases we see has continued to grow, our results have continued to improve. In 1997 there were four deaths in 603 cases, 280 of which were open heart procedures, including open heart repair in infants.

Use of **new drugs,** such as phenoxybenzanine and inhaled nitric oxide, also have had a positive impact for our patients. **Phenoxybenzanine,** a peripheral vasodilator, is used to reduce the workload of the heart in many patients, including those undergoing the arterial switch for transposition of the great arteries or the Norwood procedures for hypoplastic left heart syndrome.

Inhaled nitric oxide is an investigational drug which works as a potent pulmonary vasodilator. Its use has made it possible to avoid extracorporeal membrane oxygenation (ECMO) for some infants in end stage respiratory or cardiac failure. We use other experimental drugs in patients with idiopathic or primary pulmonary hypertension and have treated several with chronic **IV prostacyclin.**

We are proud of our program at Children's Hospital of Wisconsin. As you'll see on the following pages, our results compare favorably with programs at other well-known pediatric hospitals in the United States.

A comparison of pediatric institutions

Operations in 1995 for congenital heart defects		
institution	Operations (open and closed)	Open heart surgery
Mass.	914	649
Penn.	770	524
Michigan,	680	510
California,	550	413
California	500	400
New York	406	288
Missouri	373	269
Ohio	321	247
Children's Hospital of Wisconsin	424	242
Florida	unlisted	unlisted
Chicago	307	184

Children's Hospital of Wisconsin heart surgery by diagnosis

Year	Total Cases	Mortality rate
	Seen at the rate of .8 per 1000 new cases. No deaths in 50 consecutive cases.	
Transposition of the Great Arteries		
1998	16 cases	6 %
1994 through 1997	51 cases	2 %
Norwood Procedure		
1998	16 cases	1 death – 6 %
1994 through 1997	45 cases	27 %
Glenn Shunt (bidirectional cavo-pulmonary)		
1998	22 cases	0 %
1994 through 1997	69 cases	0 %
Fontan Procedure		
1998	16 cases	0 %
1994 through 1997	48 cases	6 %
Tetralogy of Fallot		
1998	23 cases	0 %
1994 through 1997	90 cases	4 %
Atrial septal defects		
1998	62 cases	0 %
1994 through 1997	190 cases	0 %
Complete atrioventricular canal		
1998	6 cases	0 %
1994 through 1997	49 cases	6 %
Ventricular septal defects		
1998	49 cases	0 %
1994 through 1997	111 cases	0 %
Pulmonary atresia		
1998	20 cases	0 %
1994 through 1997	38 cases	3 %
Patent ductus arteriosus		
1998	24 cases	0 %
1994 through 1997	156 cases	0 %
Coarctation of the aorta		
1998	17 cases	0 %
1994 through 1997	92 cases	2 %

Children's Hospital of Wisconsin •

Statistics from Cardiovascular Surgery
Children's Hospital of Wisconsin

5/9

Story of a non-related bone marrow donor

The Marrow of Life

Editor's note: Italicized sections of this story were taken from an essay Mary Dowd wrote for a college English class after her experience as a bone marrow donor, before she met Andrew Stasik and his family.

When I was a freshman in college, I gave about two tablespoons of blood to become a member of the National Marrow Donor Registry. I registered because one of the teammates on my field hockey team had donated her marrow one year earlier, and she convinced the nine freshmen on the team that we had no choice but to register.

Andrew Stasik is too young to understand just how important Mary Dowd is in his life.

The toddler knows only that Mary is a new friend, someone he has met only once, but who calls and sends pictures and presents.

For Andrew's parents, Ken and Linda, explaining what Mary means to their family is not so easy.

Andrew was born with severe combined immune deficiency syndrome (SCID). His body had no T-cells to fight off infections. And, although he had B-cells, they were unable to properly produce immunoglobulin, adding to his risk of developing a fatal infection. For Andrew, the colds, earaches and other ailments common to babies were life threatening.

The only cure for Andrew was a bone marrow transplant. Fortunately, Mary donated her marrow to Andrew.

After exchanging letters, e-mails and phone calls for five months, the Stasiks met Mary and her family in September 1997 when they visited Milwaukee from their North Carolina home.

"It became a group hug in about a minute," Ken said of the airport introduction. "The moment of actually meeting them, you can't describe it."

Mary recalled being overwhelmed by a wave of emotions when she saw the little boy with whom she now is permanently connected.

"I lost the capacity for words when I walked off the plane and saw Andrew," she said. "There was absolutely nothing to say. Joy and happiness filled me."

Although the meeting between the donor and recipient was a new beginning as the two families got to know each other, it also brought about a sense of closure for the Stasik family.

Understanding Andrew's illness

The SCID diagnosis did not come immediately for Andrew, who was born Jan. 18, 1995.

"He had mouth sores from birth," Linda said. "The pediatrician initially thought it was thrush."

At 4 months, Andrew was put on medication that seemed to keep the recurring mouth sores under control, Linda said.

Incredibly, she said, Andrew made it through several early illnesses. He had an ear infection, which was cleared up with medicine and at 6 months made it through a fever.

Then, in September 1995, an endoscopy through his esophagus showed a problem.

"He had thrush all down the esophagus and there was just a pinhole for air," Linda said. "His gastroenterologist (Jane Balint, MD) knew right away something was wrong."

Balint is a pediatric gastroenterologist at Children's Hospital of Wisconsin and an assistant professor of Pediatrics at the Medical College of Wisconsin.

The fact that Andrew's thrush would not go away was a warning sign to Peter Havens, MD, the Children's Hospital infectious disease specialist who diagnosed SCID that November. Havens also is an associate professor of Pediatrics at the Medical College of Wisconsin.

Once the diagnosis was made, the Stasiks' lives were turned upside down. With virtually no immune system to fight off illnesses, Andrew needed to be isolated from people or events where he could be exposed to regular childhood sicknesses such as colds, chicken pox and strep throat.

"We were told, 'from this day on your life will never be the same,' " Ken said.

Only Andrew's grandparents were allowed to visit the family at their home to avoid the risk of visitors exposing Andrew to illnesses.

For the Stasiks, the decision to go forward with a transplant was made quickly.

"The odds of him surviving without a transplant were slim," Linda said.

Next came the decision on which procedure to choose. Linda said the counseling provided by Children's Hospital pediatric oncologist Daniel Pietryga, MD, assisted them as they decided what was best for their son. Pietryga also is an assistant professor of pediatrics at the Medical College of Wisconsin.

"From the first day we met Dr. Pietryga, he has always given us his shoulder to lean on," she said.

The Stasiks had two options, according to Pietryga.

The first was for Andrew to have the bone marrow transplant, without prior treatment, to eradicate his own bone marrow and white blood cells. The transplant would provide Andrew with T- cells, which his body did not make. However, he would continue to have his own abnormal B-cells.

Andrew would have been safe from most severe infections after that procedure, Pietryga said. But, he would have had to undergo monthly infusions of immunoglobulins for the rest of his life to provide the infection-fighting substance his B-cells were unable to make.

The Stasiks opted for the second choice, a somewhat riskier process in which all of Andrew's own blood-producing cells were wiped out by chemotherapy before the bone marrow transplant.

"The benefit was that all the white cells would come from the bone marrow graft," Pietryga said. "T-cells and B-cells both would come from the graft. Lifelong immunoglobulin infusions would not be necessary."

In December 1995, after deciding to go ahead with a bone marrow transplant, Ken, Linda and Andrew's brother, Wesley, all had their blood tested for compatibility, but none were shown to be strong potential bone marrow donors for Andrew.

Luckily, by the end of January 1996, the National Marrow Donor Program (NMDP) had found

four people who were possible matches for Andrew. Mary was one of them.

As the Stasiks were discussing Andrew's options, Mary was told by the NMDP there was a baby boy who needed a bone marrow transplant and she was a possible match. Over several weeks she underwent numerous blood tests to determine whether her marrow would match the little boy's.

This waiting was strange. My life was in full swing. Spring hockey season crowded my afternoons; classes demanded my complete attention; I wondered if a little boy still was alive, and I heard nothing. Time flew at one moment and crawled at the next.

Further testing showed all eight of Mary's transplant proteins, or antigens, matched Andrew's. Six matching antigens are considered a perfect match for transplants, according to the NMDP. Mary was the only one of the NMDP's 2.8 million registered volunteer donors who was a perfect match for Andrew.

After spring break in March, I finally received a call from Scotty Lindsay, an influential member of the Carolina's Marrow Donor Program. She told me I was a perfect match with the little boy who had just survived one year of life. The waiting was over; I was going to donate my marrow.

Mary went through counseling with the NMDP to help her understand both the physical and emotional facets of donating her marrow. Afterward, she was determined to move ahead with the procedure.

"If the decision were reversed, you would want someone to do it for you," she said.

The waiting ends

Mary entered the hospital in North Carolina at 6:30 am on April 11, 1996 and was prepared for surgery.

I am not a morning person, so I was quiet and a little dazed and ready to get through the operation and the morning. My hands shook as I dressed in a gown and got on to a hospital bed in the pre-op room.

The only difficulty during the process was getting my IV needle to stay in me because my hands were sweating profusely, and the tape would not stick to my wet skin. It is a disorder I inherited from my mom that has made handshaking miserable.

After making an incision in Mary's lower back, doctors extracted Mary's marrow with a thick needle pushed through her muscle into the core of her pelvic bone, drilling 16 holes from which they extracted marrow.

The surgery was a success, but I sedate easily, so it took me a while to come to my senses. Morphine was flowing freely throughout my body, so I could not feel the 16 holes in my lower back.

I walked out of the hospital around 7 pm. Dad lifted my legs into the car, and my mom drove very slowly to the hotel. After calling my grandparents to let them know I was OK, we waited for the courier's telephone call.

I received a phone call at 11 pm from the courier. She said she saw the little boy, and he was getting his diaper changed. My marrow was then connected to his IV. All I could do was hope.

When Mary's marrow was given to the courier, she sent along a stuffed rabbit puppet and note: "Spring is a time of renewal, and I pray for your strength, your courage, and a new beginning."

Ken said he remembers the wonderment of watching Mary's marrow drip from the bag intravenously into Andrew, knowing it could save his son's life.

"We still have that bag, it's locked in a safe at home. It's a treasure to us," he said.

At the time of the transplant, the Stasiks knew only that Andrew's donor was a female college student in her early 20s and in good health. Mary knew only that her marrow was going to a baby boy.

The Stasiks and the Dowds had to wait a year to meet because the NMDP does not disclose the

identity of donors and recipients to each other until a year after a transplant, and then only if both parties want to know the information. But, through the NMDP, Ken was able to send Mary an anonymous letter after the transfusion.

Dear Donor,
I am sitting and writing this letter in my son's hospital room while at this very instant your marrow is being infused in him. Words are not easy to explain the joy my wife and I feel right now. We have cried many tears of pain until this time. When the courier arrived with your marrow, our emotions were uncontrollable. The kindness of one wonderful person to give a small part of oneself for a little child they do not know is fantastic. My wife and I would endure the pain you have gone through 100 times over for our son. We thank you for giving him the best chance he could have to lead a normal life.

Within 11 days of the transfusion, a test showed Mary's marrow had taken over. The sample showed 100 percent donor blood in Andrew's system, Ken said.

"That was an incredible feeling," he said.

Ken and Linda said the care and support the staff of the Hematology/Oncology/Transplant (HOT) Unit provided during Andrew's stay helped them understand what their son was going through. Sandy Steffes, RN, Joanne Tellock, RN, Theresa Hetlinger, RN, and Pam Versailes, RN were Andrew's primary nurses.

Moving forward

Since his transplant, Andrew has experienced a common problem for bone marrow recipients, graft-vs-host disease (GVHD). Graft-vs-host disease occurs when the transplanted marrow attacks the recipient's body.

"It's been a persistent problem," Pietryga said.

Fortunately, a new drug, mycophenolic acid, has become available for fighting GVHD. Previously, it was used to stop rejection in kidney transplants — the same basic immunologic mechanism as in graft-vs-host disease, Pietryga said.

However, the drug only can be taken orally and comes in a large capsule, which makes it difficult for many children to take. Pietryga credited pharmacist Tom Nelson, director of the Pharmacy at Children's Hospital, for finding a way to transform the medication so Andrew can drink it.

"He took the time to take apart the large capsules and put it into a form for a little boy," Pietryga said.

Andrew visits the hospital's Oncology Clinic about every other week for evaluation. Pediatric nurse practitioner Jill Perrone, RN, and Wendy Simonich, RN, have made the weekly visits as easy as possible for Andrew, Ken said.

"He's really a more relaxed kid because of them," he said.

After the transplant, Andrew never was out of Mary's thoughts as she wondered what had happened to the little boy who received her marrow.

I do not know where the little boy lives or his name, but we share a common language. Our cells are genetically the same because his body accepted my marrow. Our bodies use the same language to exist. We also will share the trauma of holding hands with someone we like: (the doctor) told me the little boy's hands might start to sweat now.

Once they were able to contact each other directly, letters, pictures, e-mails and phone calls were exchanged regularly. Ken kept a log for the 35 days before and after the transplant while Andrew was in the hospital. He sent that to Mary, while Mary shared the essay she wrote about the experience.

When the Stasiks and the Dowds started sharing family information, they found several interesting coincidences. Both Mary and Andrew's parents are named Ken and Linda and both families have two children. Wesley's favorite football team is the Carolina Panthers, which is the Dowd's home state team.

The Stasiks invited the Dowds to Milwaukee for Al's Run and Walk. The event, which was

held Sept. 27, 1997, benefits the Pediatric and Neonatal Intensive Care Units at Children's Hospital. Mary's sister, Meg, joined Mary and her parents for the trip.

Both families walked together in the annual event, for which Wesley collected pledges totaling $1,000.

The weekend the Dowds and Stasiks spent together solidified a bond that already was growing.

"It didn't seem odd at all," Mary said. "We just felt like family."

This little boy was not even born when I registered my marrow on the National Marrow Donor Registry. (Now) he can feel the warmth of his father's chest and the soft touch of his mother's hands. I have given this baby the senses I take for granted.

When I stop to turn my back to the mirror and find my small scars, I remember my awesome journey. I am aware of the details in a flash of joy. These experiences, fear, hope, pain and joy, are the marrow of my life.

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First Lady Hillary Rodham Clinton
Remarks at the Anne Hickman Lecture
Children's Hospital in Little Rock, Ark.
October 9, 1998

There is no place I would rather be whenever I come home than this hospital. I always try to think of some excuse to come by to see some of my friends that are here and see the progress that is being made and recapture the feeling that I always have when I walk through the doors here.

I was privileged in some way to help the development and expansion of this hospital and to serve on the Board of Trustees. And I have seen the miracles that happen here and the remarkable progress that is made possible because of the commitment and dedication of all of you in this room and countless others, some of whom are with us, some of whom have passed on.

I want to thank Barbara Moore, who stands in a line of excellent Chairs of the Board and is doing an excellent job. Dr. Bates, thank you for your commitment to this hospital and for inviting me to this event. I see members of the Board of the present, past and future, and I want to thank all of you. I see members of the medical and nursing staff who keep the wheels of this hospital turning and make the children and the families who are served here feel so well taken care of.

I am especially pleased, however, to be here for the event we are inaugurating today. I am a great fan and admirer of Anne Hickman, and to be asked to deliver this first lecture is a special honor for me. I also want to thank my friend, Betty Lowe. She has been a remarkable example to me over the many years that I have known her, not only here in the hospital, but many of you will recall that she was the president of the American Academy of Pediatrics and she led the medical staff here through a dramatic period of expansion and growth.

But I have known her in probably the most important role and she eluded to that. She and Bob Viser were Chelsea's doctors. And I can't tell you how reassuring it was for me to be with Betty and have her give me one of those "don't worry about that" looks. She had to do that a lot because I worry about that a lot. But she was greatly reassuring to me. Her common sense and preventive health advice put me on the right footing.

Like so many of you here today, I could hardly recognize the hospital when I saw the new Children's Nutritional Research Center -- one of only six in the nation -- the expanded neo-natal unit, a new cardiology center, a comprehensive hematology and oncology center, the new general pediatric center where children can go to be treated instead of to the emergency room.

I know how much pride all of us take in the ever-growing capacity of this hospital to serve the health needs not only of the children of Arkansas, but of children from all over the nation and even different parts of the world.

And today we celebrate the life, work and commitment to this hospital of a woman who has truly been a real spark plug -- the inspiration and the catalyst for so many of the rest of us. Barbara's tribute to Anne gave a sense of the personal commitment that Anne makes me feel toward this hospital. You just can't say no to her.

I know that many of us feel that Anne's energy kept us going when we might not have had our own to draw on. And virtually every successful program and initiative in this hospital bears her imprint. But perhaps her greatest contribution, beyond the many specific things she did, is the model she gave all of us of true civic engagement. Whether she was heading up a multi-million dollar fundraising drive or signing up volunteers to rock babies in the neo-natal unit, she showed us all what one person could accomplish.

And that is a lesson we all need to be reminded of. Anne Hickman is someone who will stay in the back of our heads on a constant basis and tell us, "Yes, we can make a difference." In fact, it is only one person that makes that decision who moves something to truly make a difference. She did that all with the grace and the humor and ability.

But we also know that Anne is not only someone who is committed to the hospital -- she has many other favorite pastimes. Whether it is being outside on a beautiful day or going fly-fishing with her grandchildren, she knows how to enjoy the gifts that life has given her. Bruce Lindsay told me yesterday that she met his Sunday school teacher, and I am particularly honored that a woman whom I admire so much and who was such a model to me and so many others would have chosen me to launch this lecture series.

I want to talk today about where we are with health care for our children. It is primarily a good news story. There is a lot to report in terms of positive accomplishments that we have seen taking place in the past several years. All of you who work day in and day out here in the hospital to improve the health and well-being know that we have worked for the past five-and-a-half years to put children's health at the top of our domestic agenda to ensure that every child in the next century will grow up healthy and strong and be prepared for the challenges that lie ahead.

If we were to take a report card on the health of America's children today, we would show that we are improving our record in almost every subject. And I am proud that much of the impetus of the work that my husband and his administration have done came directly from our experience here in Arkansas, very particularly from our experience at this hospital.

I want everyone here to know that you were our great teachers. Hearing about the needs for new technology or learning about incredible gains that could be made by simple preventive measures and outreach -- all of that was really an ongoing lesson as we saw here in Arkansas that we tried to incorporate into everything that we have done in the last years in Washington.

But if we stop to take stock, we see that today more of America's children are giving up. That is

an issue that we worked on very hard in our state and we made progress, but we didn't have a national framework or system so every state had to keep struggling to do the best that it could. And we needed to do better. And when Bill became president, we were doing better but we were not doing very well in our opinion.

We had to put in a comprehensive child immunization initiative in 1993. As a result, I can report to you, 90 percent or more of toddlers in 1996 received the most critical doses of each of the most routinely recommended vaccines. That surpasses the goal that the President set in 1993 when the legislation to set up this structure was enacted.

Also today, more of America's infants are surviving the complications of birth. We set a goal to lower infant mortality. We set goals about every 10 years. I remember back in 1980 we had been consulting with Betty and others and I served on the Southern Regional Council's Group to think about how we could try to lower infant mortality in the South to 10 per 1,000 live births.

We didn't think we would get there because we certainly have a lot of disparity between white babies and black babies; babies in rural areas and suburban areas and inner city areas. I am very pleased today to announce that we are going to be, I think, on track to achieve the year 2000 goal of reducing infant mortality to 7 per 1,000 live births three years early.

Now that is an incredible accomplishment and one that is long overdue in our nation because we have lagged behind other advanced countries in making sure that all of our babies, wherever they are born and to whatever circumstances, have a chance to survive until their first birthday.

We are also on our way to eradicating mother-to child transmission of pediatric AIDS in this country. A few years ago, pediatric AIDS was one of the 10 leading causes of death among young people. That is no longer the case. We are pleased that breakthroughs in research of AZT and other drugs enabled us to not only make this progress but then to set up a system where it could be administered to reach all pregnant women.

Today more mothers and babies are getting the care they need by being permitted to stay in their hospitals longer because of legislation that was passed in what were called "drive-by deliveries." Too many mothers were being forced out in 8, 16 or less than 24 hours, some of whom had had cesareans. That was causing problems because more and more babies were coming back into the hospital in a few days with jaundice and other problems that cost money and cause problems.

So because of the legislation that was passed, insurance companies are required to cover at least a 48-hour hospital stay for a normal delivery and 96 hours after cesareans. Today, more mothers and fathers are able to take time off from work to take children to a doctor's appointment or to be with that newborn or adopted child, thanks to the Family and Medical Leave Act.

I always refer to that first major piece of legislation that the President signed because I view it not only as a piece of legislation but as a statement of values. We really value parents and

children. We really value relationships in families. Do we create space and time for people to nurture those bonds?

Today fewer children are being exposed to lead-based paint and other environmental hazards to their health. Last year, the President signed an executive order to federal agencies, calling on them to protect children against environmental risks. That is more and more important because we are learning more each year about the environmental risks that we didn't know in the past. Chemicals, food additives and other things we didn't think were harmful we are now finding, we know now can have impacts on children and adults.

Today more poor mothers and children are eating healthier, more nutritious food because of increased participation in the Women, Infants and Children Program, the WIC Program through the Department of Agriculture. And perhaps most importantly in the long-run of the health and well-being of our children, more children are being covered by health insurance today than ever before in our nation's history.

All of us know that ongoing, primary health care is fundamental to good health and that is absolutely right. I was over here at the hospital at the hint of a sneeze to find out what was going on. And the best way, ,and often the only way, to ensure that care is to provide affordable health care coverage so that families feel that they can check up on that earache or that shortness of breath or those headaches that don't seem to go away.

The people who work at this hospital and at children's hospitals throughout the country that I have been privileged to visit are the ones who are on the front lines day in and day out. They have to deal with the emergency cases that wouldn't have been emergency cases if children had gotten regular check-ups and preventive health care.

They have to deal with those asthma attacks, high fevers and those dangerous infections that wouldn't have to be treated as seriously as they have to be now if the child has had health care coverage and a physician that could be there for that child and his family.

There really isn't any reason, or one might even say excuse, for any child to go without proper medical care in our country. Yet today, nearly 11 million American children -- one in seven -- are uninsured. And that is why expanding health care coverage, especially for children, is at the heart of the President's agenda.

Last August, with the support of a bi-partisan Congress, the President signed into law the Children's Health Insurance Program, the largest expansion of children's health care in 30 years. On that day, our nation pledged $24 billion to provide affordable health care coverage to millions of uninsured children. It created a federal-state partnership to fulfill that extraordinary promise.

Now when this law is fulfilled, we will not have universal funds because there is not enough

funds even with that commitment to reach all 11 million uninsured children, but we will certainly have made a well-deserved and long overdue down payment.

There are so many people who will benefit from the implementation of this law. Recently in Washington -- I was at the Children's Hospital there -- I met a family that was a perfect example. The father works full-time as a mechanic, the mother works full-time as a home maker. The husband gets no health insurance benefits from his job. They couldn't afford health insurance for their three sons, a 6 year old, a 3 year old and an 18 month-old. The two youngest suffered from ear infections since birth but had never had a regular hospital visit since they left the hospital.

They found out from a social worker that the two youngest were eligible for Medicaid and when they finally took them to the doctor, they found out that the 18-month-old boy had lost already 20 percent of his hearing and his speech was delayed. That meant that they had more costs and expenses ahead of them but since they finally discovered they were eligible for Medicaid, they could go ahead and afford it.

Last winter they took him in for surgery and inserted tubes into his ears and he received speech therapy. His parents finally heard him speak. That was the good news. The bad news was that although the two younger boys were eligible for Medicaid in the state they lived, namely Virginia, the older boy, at the age of 6, was too old to be eligible for Medicaid and that child was left out of medical coverage. Now that is the child that our expanded health insurance program in Virginia will cover. So that instead of two out of the three boys being covered now, all three of the children, under the Children's Health Insurance Plan, will be covered.

What is important about this, though, is not that we passed a bill and not that it has the potential for covering all these children, but that we have to implement this bill. We call it CHIP, Children's Health Insurance Plan, and it will only be effective if every young person who is eligible signs up. 49 states and territories have submitted their plans to the Department of Health and Human Services; 41 of them have been approved. As a result of this, over the next three years, about 2.3 million additional children will be covered by the approved plans.

We have to keep working with the states to make sure that they do provide adequate benefits and that they keep reaching out to cover as many children as possible. One of our fears is that some of the states might substitute for existing coverage under Medicaid lesser coverage, cheaper coverage under CHIP. So we have to keep watching this to make sure that this doesn't happen.

Some states have developed new outreach programs to make sure that families hear about what is going on. And I am pleased that here in Arkansas we are already building on innovative programs in place. If we look at the progress we made, we see that we have a long way to go but we have a good foundation to build on.

How would we do that? I think first of all, we have to go about the business of collaborating across all kinds of different lines. We have to build on the outreach work we have already started

in our communities. We have to make sure that our citizens are educated, especially parents, about what is available and how they can go about accessing it.

As successful as Medicaid has been, for example, there are an estimated 4 million children who are eligible but are still not enrolled. Now why is that? Well, there are many reasons. Some parents may not know about the program. They are unclear about whether they qualify. They are reluctant to accept government health or they are just plain confused by the complex rules and forms.

Millions of other children have parents who work hard and are just over the limit of income to qualify for Medicaid, but they cannot afford private insurance. So what we are going to be doing working with the states is trying to get information out to everybody. I am pleased to announce that the Administration is launching a radio advertising campaign to let more parents know that their children may now be eligible for health insurance.

The radio campaign will begin in nine states targeting particular families at risk and will become a part of a larger nation-wide outreach effort in January. We are going to try to learn from this to understand how we can get the message across to families to take advantage of what now is available to their children.

The federal government is taking other steps as well. The Department of Health and Human Services is working to simplify the application and enrollment procedures using a joint application for Medicaid and CHIP. Now that may sound like common sense here but believe me, that takes a lot of work in Washington to get done. We are going to get it done. We are going to make this simpler and more accessible for people.

The President's fiscal year 1999 budget includes a proposal to expand the number of places where children can be given Medicaid coverage immediately on a temporary basis while a formal application is being processed.

It is heart-breaking to hear stories about children who show up to emergency rooms, and they don't come to a hospital like this who takes everybody, but to a hospital where they sit for hours trying to figure out whether they have health insurance or not, only to be told in the end that they don't and they will have to go somewhere else.

We are trying to make it possible for every hospital, even those that are not children's hospitals, to give the care and treatment that a child who walks into an emergency room needs. The corporate, non-profit foundation and advocacy groups such as our own Arkansas Advocates for Children and Families, is also playing a critical role in reaching out to people who need to hear what they are eligible for.

In Arkansas, the outreach campaign includes TV and radio spots, color inserts in Sunday newspapers, flyers stuffed into food bags at local McDonald's restaurants -- all that will help us

succeed in making sure that we do meet the needs of our children.
We also have to be sure that we narrow the disparity between rich and poor children, Black, White and Hispanic children, because we have a lot of disparity in health care and health outcomes. We still live in a country where African American children die in infancy twice as often as White children. And where cancer and diabetes and many other diseases strike Hispanic and African-American children more frequently than White children.

And here at this hospital we know all too well that poor and minority children are far more at risk of being born with low birth rates, far more likely to die with high levels of lead in their blood and far less likely to be able to access the ongoing care they need for chronic diseases.

So we have set a goal. The President has recognized the urgency of repairing these inequities and has set the goal of eliminating racial and ethnic disparity in health by the year 2010. One step in reaching this goal is the President's proposal in this year's budget to set aside $400 million to reduce racial inequity in six major areas including immunization, cancer and AIDS. This initiative will support programs which already reach minorities effectively, but it will also provide funds for communities to learn what does work to reduce these disparities.

I will never forget one of the lessons Betty Lowe taught me so many years ago. We were both in the program called the Little Rock Junior League. Betty had spoken very effectively as always about what had to be done to improve health care of children in Arkansas. And one person asked her, "What one thing, if you could do one thing, would you do to improve the health care of children?" And I think I sort of expected her to expand the children's hospital or something like that. Instead she said she would improve sanitation and water in every part of our state.

Now it is that kind of common sense response that we have to look at because there are still places in our country where we don't have clean water or adequate sanitation facilities, where we have too many toxic waste dumps too near where kids play and live, where we can take a look at reducing these disparities in health outcomes by taking a hard look at what are the conditions that children are living in and are exposed to. It is when we can take the next, more sophisticated look at determining what it is in terms of disease, how it affects people, how they are treated for it, then can move on it.

If we do this in a very focused way, I think the President's goal will actually be reached. We also have to do more to stop children from smoking. You know, this has been a big focus of the Administration and the President in the past several years. I repeat it again today because 4.5 million children between 12 and 17 smoke cigarettes. Every day, 3,000 become regular smokers. 1,000 will die prematurely from smoking-related diseases and we will pay for many of those treatments whether they are successful or not.

So we have to do more to discourage and make it less likely that children will begin smoking. We know beyond any argument that smoking is one of the biggest health hazards we face. One way we can do that is by trying to enact comprehensive, bi-partisan legislation that imposes a

significant price increase on cigarettes and reaffirms the FDA's authority over tobacco products and imposes heavy surcharges on tobacco companies that market tobacco to young people.

I don't know if you have been to some of the inner city neighborhoods in some of our big cities that I go in and out of as I visit schools or health clinics. You would not believe the amount of advertising and the real pushing of tobacco that goes on in those neighborhoods. Of course it is not just poor and minorities and disadvantaged children that start smoking. Obviously it is children of all backgrounds and income levels.

We need to take those three steps of increasing the price, reaffirming the FDA's authority and putting a surcharge on any tobacco company which deliberately targets children -- which they are still doing today. I had a piece of correspondence that a friend of mine's child received in the mail offering all kinds of benefits -- tickets to concerts and the like -- if the child wanted to buy cigarettes.

This is something we knew would make a big dent in our health care budget and in our health care disparity so we would have to do what we can to address it. We also have to make sure that children enroll in managed care to get the health care they need. We need to do a better job of protecting the physician-patient relationship in managed care plans. We know that a lot of managed care plans are providing good, quality health care, but we also know that there are some, and unfortunately too many, who are not providing health care when it is needed in a timely manner.

The President has been fighting for a Patients' Bill of Rights so that every citizen, including our youngest, has the protections and rights she or he deserves. A patient should never have to beg and plead to see a specialist they need. A physician should not have to spend hours figuring out how to get around an HMO or other regulations to get the care that his patient needs.

When an emergency arises, they should get the care wherever and whenever they need. I met a young woman not so long ago at Cornell who said to me that she wanted to tell me her story. She had a serious auto accident on a country road. Luckily, the emergency team got them and they MediVaced her out. She spent months in the hospital and in rehab. And she is being dumped by her insurance company for the $10,000 MediVac bill because she didn't call to ask permission to be MediVaced while she was unconscious at the side of the road.

Now that is the kind of horror story which catches your attention. There are not a lot of those thankfully, but there are too many and we cannot ignore them. So we have to have a framework in which managed care delivers its services and there should be some kind of process to determine quickly when a physician believes a certain care is required. And if the HMO and the insurance company disagree, how to get that mediated.

Now when we talk about the unfinished business ahead to improve the health and well-being of our children, there is a broader agenda that that fits into. And that is the agenda of building

strong families and communities that support healthy children -- how we prepare our children for school and work and whether it is working on behalf of expanded early childhood development programs. And I see my good friend, Betty Caldwell, here who has been a pioneer in advocating for so many years the importance of early childhood education for children, whether it is Head Start, home visiting, other child care centers. Unless we really help support parents, we will not get the healthy, productive children that we should.

So we need to look at health care in a broader context and we need to be sure that we are doing what we can to support families to be able to make a difference in their own children's health care.

What is so remarkable about this hospital is that it has long recognized that it was treating the whole family, not just the sick and injured child. For those of us who had children who were patients here, we know how important it is to pay attention to the whole family and to make sure that the family understands what is being done to deal with problems that families have that might affect the well-being or the recovery of the child.

So this is really a model for what the larger agenda should be -- working to support families and strengthen families to enable parents to do the best job they can. You know that I believe and in my book "It Takes A Village" I argue that although parents bear the primary responsibility for children, we all have a role to play, whether we acknowledge it or not, in helping to support parents and families, and we all impact, directly or indirectly, on a society in which a child grows up.

I could not have been as focused on helping Chelsea grow up without the support I got at this hospital where I came for her health care, or without knowing the people and friends I had to stand with me to help meet her needs. The same is for any parent in any circumstances.

And when I am in this hospital it is possible for me to imagine a future in which all of America's children have the love and care they need to grow up strong and healthy. A future in which all of America's children have the tools of opportunity they require to live up to their God-given potential and every child regardless of their race, their background or their family's income is valued.

I want to thank every one of you here -- all of the professionals who run this hospital everyday and all the volunteers and contributors who follow the example of Anne Hickman who give so much of their heart, soul, energy and resources to make this hospital what it is -- for doing what you have done to help us move closer to that dream.

I want to keep working to make that dream a reality not only for the children of Arkansas today but for all the children to come. We could not have gotten this far without all of you, particularly Anne and her example.

Thank you very much.