

Human Rights Day '98

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December 9, 1998

REMARKS TO COMMEMORATE ANNUAL HUMAN RIGHTS DAY AND ANNOUNCEMENT
OF RECIPIENTS OF ELEANOR ROOSEVELT HUMAN RIGHTS AWARD

DATE: December 10, 1998

LOCATION: OEOB, Room 450

TIME: 9:50 AM - 10:50 AM

FROM: SAMUEL BERGER
MELANNE VERVEER
ANN LEWIS

I. PURPOSE

To commemorate the 50th anniversary of the adoption of the Universal Declaration of Human Rights, by announcing policy initiatives to advance the cause of human rights at home and abroad and honoring outstanding American human rights leaders.

II. BACKGROUND

This year's December 10 commemoration of Human Rights Day will mark the 50th anniversary of the Universal Declaration of Human Rights (UDHR).

The Eleanor Roosevelt Award for Human Rights

Eleanor Roosevelt was the driving force behind the UDHR. To honor her commitment to the principles of the Declaration, you have approved the establishment of the Eleanor Roosevelt Award for Human Rights. You have also approved the following four distinguished U.S. citizens as the awards inaugural recipients.

- Representative John Lewis, for his life-long commitment to civil rights.

- Bette Bao Lord, human rights activist, China scholar and novelist.

- Robert Bernstein, founder of the Fund for Free Expression and well as Human Rights Watch; retired Chairman of Random House.

- Dorothy Thomas, women's rights activist responsible for groundbreaking research and advocacy on violence against women around the world.

Human Rights Policy Deliverables

In addition to issuing the inaugural Eleanor Roosevelt Awards, you will deliver general remarks that include announcement of several new initiatives. They include:

- Human Rights Executive Order, reiterating our commitment to implementation of those human rights treaties we have ratified, and creating an Administration working group to monitor implementation and to consider our position in other human rights instruments.

- Establishment of a Genocide Early Warning Center that will focus intelligence resources on situations that could become genocidal.

- Enhancing our response to human rights emergencies by funding nongovernmental organizations to develop rapid response capacities.

- Increased assistance to victims of human rights abuse through the funding of efforts to assist human rights victims, including Afghan women and survivors of genocide, as well as a substantial increase in our contribution to the U.N. Voluntary Fund for Torture.

- Combating child labor by contributing \$30 million this year to the ILO's International Program on the Elimination of Child Labor, a tenfold increase over last year's \$3 million contribution.

- Protecting abused workers in the United States by submitting a legislative proposal to permit illegal aliens who are the victims of serious abuses in the United States to gain lawful status if they cooperate with authorities in identifying abusers.

- Preventing youth hate crime through the Department of Education's publication of a "Harassment and Hate Crimes Guide for Schools."

- Issuance of new guidelines for the adjudications of asylum claims by children in the United States.

III. PARTICIPANTS

(Greetings in OEOB Room 450 "Hold Room")

Representative John Lewis
Bette Bao Lord
Robert Bernstein
Dorothy Thomas

The First Lady
Sandy Berger

Melanne Verveer
Eric Schwartz

IV. PRESS PLAN

Open press coverage of remarks made in OEOB Room 450.

V. SEQUENCE

- You will greet the award recipients in the OEOB Room 450 "Hold Room."
- Sandy Berger, Melanne Verveer, and Eric Schwartz will take their seats in room 450 OEOB.
- Following an off-stage announcement, you will take the stage of room 450 accompanied by the First Lady, Representative John Lewis, Bette Bao Lord, Robert Bernstein and Dorothy Thomas.
- The First Lady will deliver brief welcoming remarks and will introduce you.

- You will deliver remarks on human rights and will announce the creation of The Eleanor Roosevelt Award for Human Rights.
- A military aide will read the citations as you and the First Lady present the awards to the recipients. The four awardees will not make remarks.
- Following the awards ceremony, you will thank the guests and work a rope line.

Attachments

Tab A Biographies of the Four Awardees

Tab B List of Invitees

TAB A

ROBERT BERNSTEIN

Robert Bernstein has devoted his life to the active defense of freedom of expression and to the protection of victims of injustice and abuse throughout the world. Throughout his career, human rights has been his guiding passion. As Chairman, President, and Chief Executive Officer of Random House, Mr. Bernstein has given voice to persecuted individuals and minorities and has defended authors throughout the world from attempts to silence them or otherwise restrict their right to free expression. Since the early 1970s, he has worked inexhaustibly for the cause of human rights, and has founded, led, and inspired an array of human rights organizations in the United States. Twenty years ago, Mr. Bernstein founded Human Rights Watch, now one of the largest and most effective human rights advocacy organizations in the world.

Mr. Bernstein rose from office boy at Simon & Schuster in 1946 to current Chairman, President, and Chief Executive Officer of Random House, Publisher-at-Large with John Wiley & Sons, and publishing consultant to the New York Public Library and the American Museum of Natural History.

In 1971, Bob Bernstein visited the Soviet Union as part of a publishing delegation traveling to encourage Soviets to join the International Copyright Convention. Through his interpreter and guide, dissident Anatoly Shcharansky, Bob Bernstein learned about the general atmosphere of suppression and about the courage and principles of Andre Sakharov and others. On the strength of his convictions, Mr. Bernstein refused to do business with the Soviet Union, and instead began publishing the works of repressed writers. Random House became publisher of many banned works from all over the world. Among the writers Bob Bernstein published over the years were: Andrei Sakharov, Elena Bonner, Natan Sharansky, Vaclav Havel, Jacobo Timerman, Lev Kopelev, Andrei Amalrik, Roy and Shores Medvedev, Vasily Aksyonov, and Wei Jingsheng. As Mr. Bernstein once explained, "It was their only voice to the outside world."

Following his early trip to the Soviet Union, Bob Bernstein urged the Association of American Publishers (AAP) to use the occasion of the signing of a "publishing protocol" with the Soviet Union as leverage for the release of Soviet writers imprisoned for expressing their thoughts. From this debate and conflict among publishers, arose a new committee within the AAP, the International Freedom to Publish Committee (IFTPC), initially with Mr. Bernstein as its head. The IFTPC functions as the AAP's moral conscience and human rights arm. In 1975, Bob Bernstein also founded the Fund for Free Expression (FFE), an independent human rights group which included many well-known U.S. writers, such as E.L. Doctorow, Anthony Lewis, Toni Morrison, and others concerned with free expression issues.

In 1978, Bob Bernstein received a two-year Ford Foundation grant to set up offices for Helsinki Watch. The organization was part of the follow-up to the 1975 Helsinki Accords which linked peace and economic cooperation with human rights. Helsinki Watch was created as a citizens group to monitor human rights abuses in the Soviet Union and Eastern Europe and offer moral support to persecuted colleagues elsewhere and publicize their plight.

FOR FORTY YEARS JOHN LEWIS HAS BEEN AT THE VANGUARD OF CIVIL RIGHTS ACTIVISM IN THE UNITED STATES. AS A LEADER OF ORGANIZATIONS LIKE THE STUDENT NON-VIOLENT COORDINATING COMMITTEE AND THE VOTER EDUCATION PROGRAM, AND LATER AS A MEMBER OF THE ATLANTA CITY COUNCIL AND THE U.S. HOUSE OF REPRESENTATIVES, HE HAS HELPED EDUCATE AND MOBILIZE GENERATIONS OF YOUNG AMERICANS IN THE CRUSADE AGAINST INJUSTICE. THROUGH HIS LEADERSHIP OF AND PARTICIPATION IN SIT-INS, FREEDOM RIDES, PROTEST MARCHES AND VOTER REGISTRATION DRIVES IN THE 1960S, HE CAME TO SYMBOLIZE THE COURAGE AND DEDICATION OF THOUSANDS OF ACTIVISTS FIGHTING FOR EQUAL PROTECTION AND EQUAL RIGHTS UNDER THE LAW. HE SUFFERED MORE THAN FORTY ARRESTS, PHYSICAL ATTACKS, AND SEVERE INJURIES, YET NEVER ONCE DEVIATED FROM HIS FIRM COMMITMENT TO NON-VIOLENT DIRECT ACTION. WE HONOR HIM TODAY FOR HIS UNCOMPROMISING HEROISM IN THE FACE OF BIGOTRY, HATRED, AND VIOLENCE, AND HIS UNSWERVING COMMITMENT TO THE PRINCIPLES OF THE UNIVERSAL DECLARATION OF HUMAN RIGHTS.

Born outside Troy, Alabama in 1940, John Lewis grew up on a tiny family farm without plumbing or electricity. The first member of his family to graduate from high school and later college, Lewis has been a Member of Congress since 1981.

Yet describing John Lewis as an American success story fails to capture the life of one of the more remarkable individuals of this century. As a young man, Lewis was determined to become a preacher. At age fifteen, he discovered Martin Luther King, Jr., who was then only beginning his own efforts on behalf of human rights. After graduating from high school, Lewis traveled to Nashville to study at the American Baptist Theological Seminary. He soon discovered the Highlander Folk School, where he studied the principles of Gandhian nonviolence and met civil rights pioneers like Diane Nash and Septima Clark.

In the summer of 1960, Lewis began to help organize some of the earliest sit in campaigns in Nashville, Tennessee. Over the next two years, he helped transform the face of Nashville by leading sit-ins that desegregated churches, department stores, libraries, restaurants, theatres, and other establishments. As one author later noted, "he [marched] through Nashville's yellow pages." In 1961, he volunteered to help lead the Freedom Rides, a campaign to desegregate interstate bus service. For his efforts, Lewis was beaten by an angry mob.

Similar efforts by other students throughout the American South led Lewis and other students to form the Student Non-violent Coordinating Committee (SNCC), which soon became one of the nation's most influential civil rights organizations. By 1963 – as the 23 year-old chair of SNCC – Lewis already was one of the nation's most prominent civil rights

activists. That year, he helped organize the historic "March on Washington," at which he was a keynote speaker. In 1964, he helped coordinate SNCC-led voter registration drives and community action programs during the Mississippi Freedom Summer.

In 1965, Lewis turned his attention to the community of Selma, Alabama, where he helped organize efforts to register African-American voters. As part of that campaign, leaders organized a march to the state capitol of Montgomery to demand the right to vote. On Sunday, March 7, Lewis and Hosea Williams led 525 men and women across the Edmund Pettus Bridge, where Alabama state troopers halted the marchers and ordered them to return to their homes. When the marchers held their ground, the troopers attacked with nightsticks and tear gas. Lewis and several other protesters were severely beaten in what became known as "Bloody Sunday." The courage of Lewis and other marchers in the face of such violence served as the impetus for the passage of the Voting Rights Act.

After leaving SNCC in 1966, he remained active in the movement through his participation in the Southern Regional Council's voter registration programs. Lewis later became Director of the Voter Education Project, which, under his leadership, added nearly four million voters to the rolls.

In 1977, President Jimmy Carter appointed Lewis to direct the more than 250,000 volunteers of ACTION. In 1981, Lewis was elected to the Atlanta City Council. In 1986, Lewis won election to the U.S. House of Representatives, where he represents Georgia's Fifth Congressional District. During his twelve years in Congress, Lewis has drawn praise for his continued commitment to the principles of civil rights and human justice.

Jackie Robinson, recipient of the American Library Association Award. *Spring Moon* is about a family saga set against a backdrop of the cultural and political upheavals that have taken place in China over the past century. Mrs. Lord originally planned to write non-fiction, but later decided to write a historic novel instead, fearing that her relatives in China might otherwise suffer reprisals because of the Cultural Revolution. She appears frequently on national television news programs, such as *The Lehrer News Hour*, *Face the Nation*, *Larry King Live*, *20/20* and others, and has contributed essays to *Newsweek*, *USA Today*, and other domestic and international periodicals.

BETTE BAO LORD

Bette Bao Lord (democratic rights, novelist, human rights)

Bette Bao Lord is a novelist and human rights activist, who has dedicated her life to the pursuit and defense of liberty. She currently serves as Chairman of Freedom House, an organization founded over fifty years ago by Eleanor Roosevelt, Wendell Willkie, and other Americans concerned with threats to peace and democracy.

Mrs. Lord is an active campaigner for political rights and civil liberties worldwide. At age eight, she emigrated with her family from Shanghai to the United States. Mrs. Lord returned to China as wife of Ambassador Winston Lord and served as CBS News consultant during the June 1989 Tiananmen Square protest.

Mrs. Lord has bridged communities, bringing together democracy and human rights advocates, political leaders of different parties, non-governmental and governmental players, and citizens groups from different countries. Non-partisan and broad-based, Freedom House is led by a Board of Trustees composed of leading Democrats, Republicans, and independents; business and labor leaders; former senior government officials; scholars; writers; and journalists. All are united in the view that American leadership in international affairs is essential to the cause of human rights and freedom.

Freedom House is a clear voice for democracy and freedom around the world. Under Mrs. Lord's leadership, Freedom House has expanded its reach, strengthened its previous programs, and broadened its support. Every year, Freedom House publishes *Freedom in the World*, a comparative assessment of the state of political rights and civil liberties in 191 countries; *Press Freedom Survey*, a country-by-country, worldwide assessment of press freedom; and *Nations in Transit* a comprehensive report on the status of the political and economic reforms in the emerging democracies and transitional countries of Eastern Europe and the former Soviet Union. In addition, Freedom House publishes *Freedom Review* reports on important domestic and foreign policy issues and publications from its Center for Religious Freedom, which reports on the religious persecution of individuals and groups abroad.

The legacy begun by Eleanor Roosevelt and other founding members of Freedom House continues. Over the past decades, Freedom House has been a vigorous proponent of democratic values and a steadfast opponent of dictatorships of the far left and the far right: in Central America and Chile, apartheid in South Africa, the suppression of the Prague Spring, the Soviet invasion of Afghanistan, genocide in Bosnia and Rwanda, and the brutal violation of human rights in Cuba, Burma, China, and Iraq. It has championed the rights of democratic activists, religious believers, trade unionists, journalists, and proponents of free markets. In the words of President Clinton, "For more than fifty years, Freedom House has been a voice for tolerance and human dignity. People all over the world are better off because of your work."

Mrs. Lord is the author of *Legacies, A Chinese Mosaic* (on *Time* magazine's 1990 ten best non-fiction books list), *Spring Moon* (*New York Times* bestseller list for seven months), *Eighth Moon*, published in fifteen foreign language editions and *In the Year of the Boar and*

In 1981, Bob Bernstein created Americas Watch and later additional Watch Committees to cover every region of the world - Helsinki, Americas, Asia, Middle East, and Africa. IN 1987, Mr. Bernstein established and became the chair of Human Rights Watch, the parent organization linking the various watch committees. A few years later, three thematic projects were added on women's rights, children's rights, and arms transfers. Under Bob's leadership, Human Rights Watch has grown from a small group of concerned citizens with an annual budget of \$200,000 to a large professional organization of over 100 people dealing with more than 70 countries and a yearly operating budget of 12 million dollars.

Human Rights Watch has become widely known for its documentation of abuses and its hard-hitting advocacy in the press and with governments. It has been a pace setter within the human rights movement, pushing the boundaries of its mandate to include violations of the Geneva conventions by governments and guerilla groups, and to focus on specific categories of rights, such as women's rights, children's rights, gay and lesbian rights.

Bob Bernstein has received numerous honorary degrees and awards in recognition of his accomplishments. In addition to the organizations he himself has founded, Mr. Bernstein serves on the boards of a number of human rights organizations and of foundations that support human rights. Among them are the Lawyers Committee for Human Rights, the International League for Human Rights, the International Helsinki Federation, Human Rights in China, the Robert F. Kennedy Human Rights Award, the Carter-Menil Human Rights Foundation, and the Aaron Diamond Foundation. He also serves as Chairman of the Association of Publishers, and on the board of the American Book.

As founder and director of the Human Rights Watch Women's Rights Division, Dorothy Thomas has not only advocated for the human rights of women, but has ever expanded the ways in which these rights are understood. Within the last decade, it was Thomas' advocacy that helped persuade the United Nations and the world that crimes against women such as forced prostitution and systematic rape were indeed "gross violations of fundamental human rights." From establishing a program to monitor and combat state-sponsored violence against women worldwide to augmenting the links between domestic advocacy groups and the international women's human rights movement, Thomas has proved an innovative and uncompromising achiever. Her publications on women's human rights issues cover regions as diverse as South Africa, Poland, Brazil, Kuwait, and the United States.

Presently Thomas has focused her concerns domestically, seeking to consider the lives of American women, and particular those involved in the American prison system, in light of international standards. "When you say 'human rights,' people think it applies only to women elsewhere," she says. "I'm obsessed with changing that." A two-time graduate of Georgetown University, Thomas has recently received the MacArthur Foundation.

TAB B

AFL-CIO

John Sweeney, President
Barbara Shailor, International Affairs

American Friends Service Committee

James Matlack, Director
Washington Office

American Arab Anti-Discrimination Committee

Hala Maksoud

Amnesty International USA

William Schulz
Steve Rickart

Anti Defamation League

Howard Berkowitz, Natl. Chair.

Arab American Institute

James Zogby

Baha'is of the Americas

Kit Cosby

The Carter Center

Ambassador Harry Barnes

Center for Policy Alternatives

Linda Tarr-Whelan

Committee to Protect Journalists

Ann Cooper

Communications Consortium

Kathy Bonk

Disabled Peoples' International

Lucy Wong-Hernandez

Feminist Majority Foundation

Eleanor Smeal

Foundation for a Civil Society

Wendy Luers

Freedom House

Adrian Karantnycky, President
or representative

Holocaust Museum

Miles Lerman

Human Rights Action Center

Jack Healy, President

Human Rights Watch

Ken Roth

IFES (International Foundation for Election Systems)

Richard Soudirette

International Human Rights Law Group

Gay McDougal

International Labor Rights, Education, and Research Fund

Pharis Harvey

International League for Human Rights

Cathy Fitzpatrick, Executive Director
Scott Horton, President

International Republican Institute

Lorne Craner

Jacob Blaustein Institute for the Advancement of Human Rights

Felice Gaer, Director

Jewish Council for Public Affairs

Lynn Liss

Lawyer's Committee for Human Rights

Michael Posner, Executive Director

Leadership Conference on Civil Rights

Wade Henderson, Executive Director

NAACP

Kwasi Mfume

NAACP Legal Defense and Education Fund, Inc.

Ms. Elaine Jones, Director

National Council of the Churches of Christ
Rev. Dr. Joan Brown Campbell, General Secretary

National Council of La Raza
Raul Yzaguirre, President and CEO

National Child Labor Committee
Dorianne Beyer, General Counsel

National Conference of Catholic Bishops
Most Rev. Theodore McCarrick
Roman Catholic Archbishop of Newark

National Council of Negro Women
Dr. Dorothy Height, Chair

National Day of the Persecuted Church
Clyde Taylor

National Democratic Institute
Ken Wollack, President

National Endowment for Democracy
Carl Gershman

National Gay and Lesbian Task Force
Kerry Lobel, Executive Director

Open Society Institute
George Soros
Aryeh Neier

Organization of Chinese Americans
Daphne Kwok, Executive Director

Physicians for Human Rights
Len Rubenstein
Holly Burkhalter

Rainbow Coalition/Operation Push, Inc
Jesse Jackson, Sr., President and CEO

Religious Action Center
David Saperstein

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HEADLINE: Recognizing a 'miracle' The high-fat ketogenic diet can ease seizures in epileptic children

BYLINE: Kathleen Fackelmann

BODY:

You know you've produced a hit TV movie or series when it develops its own spin-off -- another show that sustains the impact of its original.

For writer/director Jim Abrahams, the most significant spin-off from his 1997 TV movie, *First Do No Harm*, had nothing to do with entertainment but a lot to do with the health of his epileptic son and thousands more like him.

The movie, starring Meryl Streep, captured a Chicago family's struggle to conquer the seizures racking their son's body.

Abrahams was uniquely qualified to write and direct the movie. He and his wife, Nancy, would never forget their own fight to save their son Charlie when standard epileptic drugs and even brain surgery could not halt the brainstorms that seized his small body.

In desperation, they turned to the ketogenic diet, a controversial regimen that involves feeding children huge amounts of fat. The diet is thought to help some children by inducing a seizure-calming condition called ketosis. Ketosis occurs when the body is forced to burn fat instead of sugar.

The diet can be risky. But it can represent the only hope for children who don't respond to standard treatment.

Within 72 hours of starting the diet, Charlie was seizure-free. "We felt as though we had had a miracle," recalls Abrahams, who in 1994 started the Charlie Foundation to Cure Pediatric Epilepsy.

While Abrahams' other films such as *Airplane!* gave fans a laugh a minute, *First Do No Harm* fueled a grass-roots effort for more research on the diet, says John Freeman, the neurologist at the Johns Hopkins Medical Institutions in Baltimore who treated Charlie.

That groundswell is paying off. In December, Freeman and colleagues published the largest, most definitive study to date of the ketogenic diet.

The findings, reported in Pediatrics, confirm research suggested the diet does control seizures in some children. Additional new studies highlight a naturally produced substance that may underlie the diet's success.

Neurologists, who even a few years ago had viewed the diet with extreme skepticism, are now acknowledging its value. "There's recognition now," says Harvard neurologist Steven Schachter. "This form of therapy does have a role to play" in treating some cases of pediatric epilepsy, he says.

About 350,000 children and teen-agers suffer from epilepsy, a disorder with a variety of causes that leads to a disturbance in the brain's electrical activity. Doctors can harness seizures 80% of the time with drugs. But for the others, drugs simply don't work.

Doctors said Charlie's seizures would ultimately damage his brain, leading to mental retardation. "You feel your child has been given a fate worse than death," Jim Abrahams says. That frustration led the Abrahamses on a search that brought them to Freeman, who used the diet to treat a handful of children each year.

Because no rigorous scientific study of the ketogenic diet had been done, most neurologists discounted it as unproved and potentially unsafe. Indeed, the Abrahamses had taken Charlie to top pediatric neurologists in the USA. Not one mentioned it as an option.

The new research has given the ketogenic diet the credibility it had long been lacking. In the Pediatrics study, Freeman and his colleagues examined 150 children ages 1 to 16 who continued to have seizures despite treatment with at least two anticonvulsant drugs.

Doctors first hospitalized the children for five days, then gradually weaned them off their usual diet and put them on the ketogenic diet.

Kids on the regimen eat a high-fat, low-protein, low-carbohydrate diet.

Meals typically include small amounts of fish, meat, poultry, fruits and vegetables and lots of added fat, usually in the form of butter, oil or heavy cream.

The diet provides a whopping 90% of total calories from fat, says Jane McGrogan, a nutritionist at the Hopkins program. The average American diet gets between 30% and 40% of its calories from fat.

Kids love the cream but generally don't like the limits on sugar and carbohydrates. They must avoid pastries, sugary soda pop, potato chips and pretzels, McGrogan says.

Ten-year-old Timothy Finnigan of Satsuma, Ala., says the diet can be tough to follow. "It's hard when you look at what everyone

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else is eating," says the fifth-grader, who brings his lunch to school.

The diet also puts demands on parents, who must weigh foods and keep strict tabs on calories. Most parents find they must prepare meals without the help of processed foods, which can contain hidden carbohydrates, McGrogan says.

Still, the Hopkins team found that most parents and their children successfully followed the diet. The researchers found that 55% of children who started the diet stayed on it for a year. Nearly all of those children had fewer seizures on the diet, with 27% getting almost complete relief.

"These are the most desperate cases," Freeman says. "Even in those we get a spectacular success rate."

Children who stopped the diet usually did so because it wasn't working, Freeman says.

Freeman thinks the diet shouldn't just be a last resort but ought to be considered earlier. That may happen as doctors learn of a new study by Charles Niesen of the University of Southern California in Los Angeles. His findings show that a naturally produced substance called beta-hydroxybutyrate (BHB) may explain how the ketogenic diet works.

Niesen and researcher Sara Lustig designed a rat study to test one of a group of substances called ketones manufactured by the liver during the ketogenic diet. The diet forces the body to burn fat instead of sugar, producing BHB and other ketones during that process.

The researchers found BHB could block seizures in the rats. "We actually prevented seizures in 50% of the animals," Niesen says. The team presented results in December at the American Epilepsy Society's annual meeting in San Diego.

Niesen's research suggests that BHB calms the brain's electrical disturbance by activating certain protein receptors on brain cells. That raises hope that BHB in drug form will stop such brainstorms.

If Niesen gets Food and Drug Administration approval, he could launch a study of BHB in children as early as this spring. "I'm eager to get the kids started," he says.

Meanwhile, another study presented at the December meeting indicates that doctors can fine-tune the ketogenic diet to produce the most beneficial levels of BHB in the blood.

Lawrence Brown, Claire Chee and their colleagues at the Children's Hospital in Philadelphia developed a device to keep track of BHB in the blood of 12 epileptic children who were on the ketogenic diet. When eight of the 12 suddenly started having more seizures, the team found the level of BHB in the blood had dropped. The

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researchers adjusted each child's diet to boost BHB, bringing seizures under control within 12 hours, Brown says.

Just as a diabetic keeps track of insulin, children with epilepsy one day may be able to check their BHB levels at home to make sure the diet is working properly, Brown says.

Although parents might be tempted to view the diet as a natural approach to the treatment of epilepsy, researchers warn that the diet is harsh.

"You're using the diet as a drug," says Philip Sheridan, an epilepsy expert at the National Institutes of Health in Bethesda, Md. Parents who want to consider the ketogenic diet should carefully weigh the risks, he says.

According to Sheridan, those include kidney stones, immune system abnormalities, low blood sugar and clogged arteries. Sheridan worries that the high-fat diet may set the stage for a heart attack later in life.

Many children can be weaned off the ketogenic diet within a few years, Freeman says. Some go off the diet and remain seizure-free, he says.

Yet some children, like Charlie Abrahams, must stay on the diet or the seizures return. No one really knows the effects of maintaining a child on such a diet for years or even decades, Sheridan says.

Freeman worries that such children may be vulnerable to growth retardation. Freeman, Sheridan and other experts advise parents to go on the diet only with the appropriate medical and nutritional help. Parents who have tried this diet on their own have had tragic results, Freeman says; several children have died as a result of an unsupervised ketogenic diet. The risks of an unsupervised diet include malnutrition, vitamin deficiencies and chemical imbalances.

At Johns Hopkins, the staff monitors children closely to make sure they're well-nourished and growing properly.

For Charlie, and many children like him, the future appears considerably brighter today than it did five years ago. In 1993, the Hopkins program was one of only a few that parents could turn to for the ketogenic diet. Now, many major medical centers offer it.

And research on the diet has exploded. The 1993 Epilepsy Society's meeting had no papers on the ketogenic diet, Freeman says. This year, 23 researchers presented findings.

The new era "provides hope for my family and lots of other families," Abrahams says.

For more information on the ketogenic diet, call the Charlie Foundation at 800-367-5386.