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At Risk for Huntington's Disease

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## A veteran neurologist's book offers tools for navigating the 'turbulent world' of Huntington's disease

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# At Risk for Huntington's Disease

*HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.*

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WEDNESDAY, DECEMBER 30, 2020

## A veteran neurologist's book offers tools for navigating the 'turbulent world' of Huntington's disease

In the fight against any disease, affected individuals and health professionals can arm themselves with an invaluable tool: detailed, cutting-edge knowledge about a condition's medical and social impact.

For the Huntington's disease community and related disorders, Thomas Bird, M.D., has made a key contribution with his book [Can You Help Me? Inside the Turbulent World of Huntington Disease](#), published last year (Oxford University Press).

A retired neurologist who has observed more than 1,000 individuals with HD, Dr. Bird has produced one of the most important – and most accessible – introductions to this devastating disorder. *Can You Help Me?* will remain relevant for years.

[Dr. Bird](#) is an Emeritus Professor of Neurology and Medical Genetics at the University of Washington in Seattle, WA. His career spanned more than 40 years, including pioneering work in the field of clinical neurogenetics (diagnosing and evaluating hereditary nervous system disorders). His patients included sufferers of Alzheimer's disease (AD), Parkinson's disease (PD), and other severe, chronic brain conditions.

“I have been [...] constantly amazed, puzzled, distressed and impressed by the trials and tribulations of these families coping with it,” Dr. Bird writes of Huntington's. (As with some in neighboring Canada and elsewhere, he calls it “Huntington

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## HD Blogs and Individuals

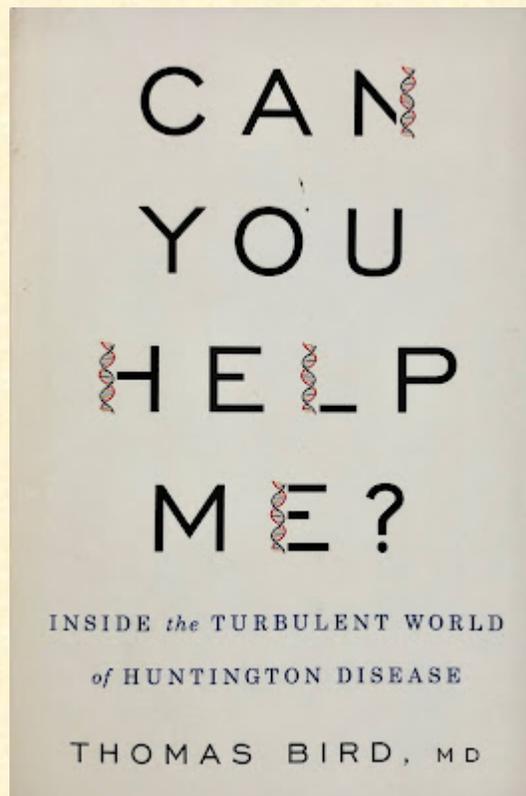
[Chris Furbee: Huntingtons Dance](#)  
[Angela F.: Surviving Huntington's?](#)  
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disease.”) “Dealing with HD has been so moving, so unsettling and so challenging for me that I felt compelled to write about it.”

“Can you help me?” a desperate HD-affected man wrote Dr. Bird from the state penitentiary in 1980 seeking medical assistance. That question reverberated in Dr. Bird’s encounters with many other HD people and their families and caregivers.

With non-technical, limpid prose, Dr. Bird tells the full story of HD’s wide-ranging medical, socioeconomic, and legal implications through a series of poignant vignettes, based on hundreds of HD cases. He changed identifying information to preserve patient privacy, and in some cases created composites of two or three different individuals.

*Can You Help Me?* will ring familiar to veterans of the HD cause, but it also offers new revelations and insights about HD’s impact. Also, it provides an excellent primer for families new to HD.



**Key lessons about bioethical challenges**

Many of the stories in *Can You Help Me?* center on the bioethical challenges faced by HD families, such as the complex ramifications of genetic testing.

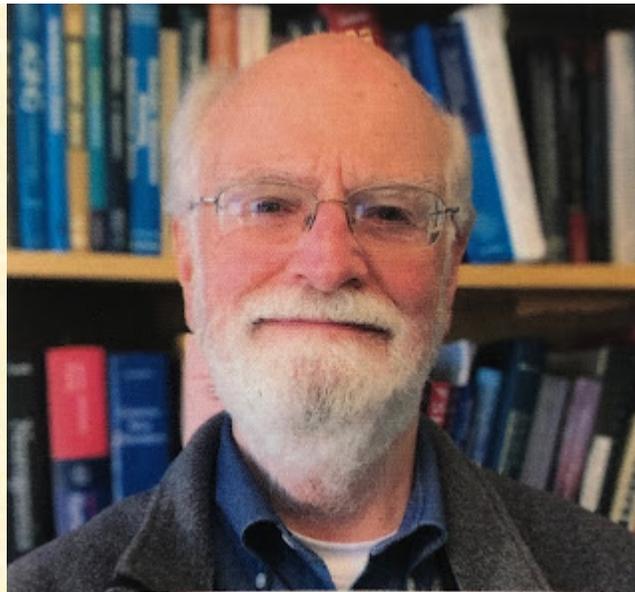
Dr. Bird retells the story of a deeply troubled young man from an HD family killed by the police after a life of drug use and many clashes with the law – anti-social behavior perhaps resulting from the disease. The man's aunt pleaded with Dr. Bird to have the coroner confirm the man's HD status, because he had a three-year-old daughter for whom the test result would someday hold great relevance. Divorced, the man had lost contact with the mother.

“Needless to say, this was uncharted territory for us,” Dr. Bird writes of his clinical team. “The appropriate legal or ethical aspects of this case were not clear to me, but I called the University Hospital genetics lab and explained the situation.” On Dr. Bird's orders, the lab performed the test.

The test demonstrated that the man indeed did have HD – “another burden” for the extended family, as Dr. Bird writes.

“To this day, I do not know if we followed the correct strategy in trying to help this family,” he concludes. It seemed like “quick thinking” to ask the coroner to save a sample of the dead man's blood for HD testing, he observes. But many questions remained, including when and how to tell the girl of her at-risk status, he adds.

Dr. Bird believed that he might encounter the family again, when the little girl had grown up.



*Dr. Thomas Bird (book jacket photo by Chang En Yu)*

### **No 'typical' patient**

In an appendix, Dr. Bird provides an overview of the genetics of HD and the genetic testing process. In general, as I noted in a [previous article](#), Dr. Bird's book has helped move the HD field from a traditional, more limited kind of genetic counseling to broader "genetic education."

*Can You Help Me?* reflects on many other key issues for the HD community.

He offers valuable insight into the challenges faced by health professionals working with HD patients, as exemplified in the story of a patient clinic who shot himself. "Could we have done more?" Dr. Bird asks. "These situations are heavy burdens for everyone to bear."

Dr. Bird's vignettes underscore another crucial point in line with the latest medical and scientific research into the disease: there is no "typical" HD patient, as symptoms manifest uniquely in each case.

Notably, Dr. Bird does *not* describe HD as being like a combination of other diseases such as AD and PD, a shorthand

some in the HD community use. Dr. Bird instead compares HD to these and other conditions, thus adding vital context.

Dr. Bird also emphasizes the need to end the false dichotomy between psychiatric “mental” diseases like schizophrenia and “brain” diseases like HD. Both originate in the brain, he points out, and both cause “mental illness.” Psychiatry and neurology should intersect more, he argues.

### **A contribution to the history of HD**

In researching the book, Dr. Bird did important historical legwork. For instance, he painstakingly tracked down important episodes such as the use of lobotomies as an attempt to treat HD.

“It is estimated that 50,000 lobotomies were performed in this country between 1938 and 1955,” Dr. Bird writes. “Since persons with HD were often institutionalized and lobotomies were common, it is likely that many of these operations were performed on patients with HD.”

Although the procedures on HD people were “not easy to document,” Dr. Bird finally found evidence by examining medical texts. In all, Dr. Bird estimates that “perhaps more than 100” people with HD had the operation. It is *not* currently recommended for HD.

### **A ‘Princess in Pink’**

Although many vignettes are gut-wrenching, *Can You Help Me?* also highlights the sometimes-brighter side of the HD story, such as individuals with late onset, mild symptoms, and productive lives.

That message holds two-fold meaning for me as an asymptomatic 61-year-old HD gene carrier who saw his mother develop the disease in her late 40s and die at 68.

First, I remember how fortunate I am to have reached this stage [without symptoms](#).

Secondly, as a writer and advocate, it reminds me that, no matter how badly the disease has turned people like my mother into shadows of themselves, we should see them as humans struggling with disabling symptoms.

A caring community can seek to alleviate some of that burden.

One of my favorite stories from *Can You Help Me?* spotlights the “Princess in Pink,” Bobbi, a little girl who, although afflicted with juvenile HD, maintained her cheerfulness.

Bobbi’s fifth-grade teacher, Miss Perry, “decided to be proactive,” Dr. Bird writes. “She wanted to make Bobbi more comfortable in the classroom and educate her other students about Bobbi’s disease and how to relate to persons with disabilities.”

The class created the “Princess Project” to discuss HD and create a booklet – with a pink cover and a picture of Bobbi wearing a pink crown – about Bobbi and her condition. The classmates wrote perceptive and compassionate entries and also made drawings of Bobbi.

“It was a learning experience for everyone, including the adults,” Dr. Bird recalls.

Sadly, by age 15, Bobbi’s condition worsened, requiring a feeding tube, a frequent end-of-life measure for HD patients. She died in a hospice setting. Several of her old classmates attended the memorial service, where they fondly remembered Bobbi, Dr. Bird writes.

### **A resounding ‘yes’ in wanting to help**

*Can You Help Me?* is one of the best and most important books about HD. It builds on the work of historian Alice Wexler, in particular her book [The Woman Who Walked into the Sea](#), which uncovers many of the prejudices associated with HD ([click here](#) to read my review).

Dr. Bird has provided us with a deeply rich documentation of life in the HD trenches.

The title *Can You Help Me?* asks a question that I and so many other HD family members have posed when confronted with the frightening prospects of HD. (It also holds great value for people in the AD, PD, and other neurological disease communities.)

“Sometimes we can help a great deal, sometimes we can only help a little, and sometimes we just muddle through as best we can, navigating our way between suffering and harm,” Dr. Bird concludes, noting briefly that research towards treatments “heralds better days ahead for the world of HD.”

Fortunately, for the HD community, Dr. Bird’s book indicates a resounding “yes” regarding the desire by him and so many other professionals to alleviate the suffering caused by HD.

(For an interview of Dr. Bird about the book, [click here](#)).

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Posted by [Gene Veritas](#) at 12:10 PM      

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