

Harrison Ford gives “action hero”
new meaning as he takes
Extraordinary Measures to bring
to the big screen the real-life
quest to cure a rare disease

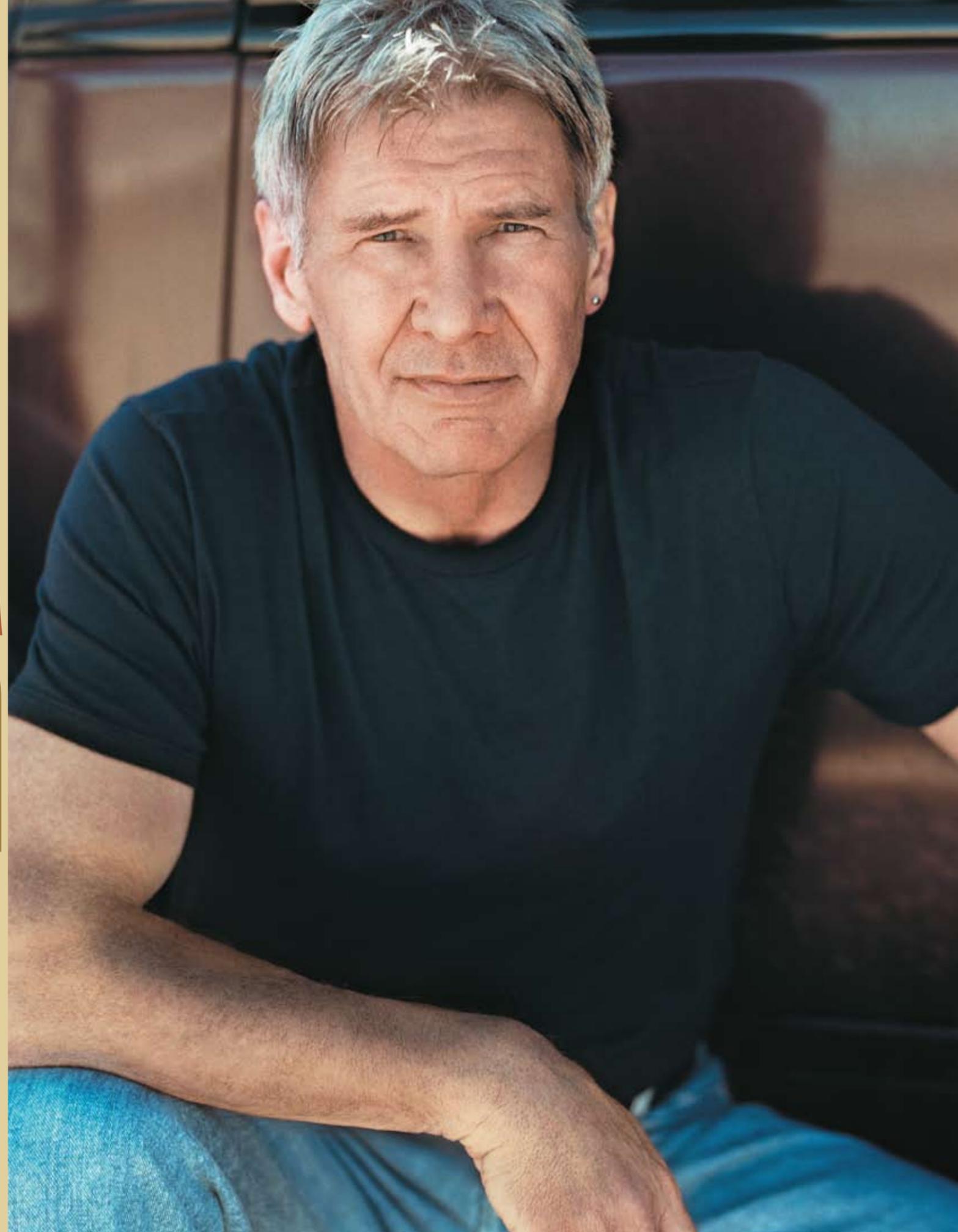
Ford Tough

In the new film *Extraordinary Measures*, Harrison Ford does what he does best. The veteran actor brings to life another curmudgeonly character who, once his prickly exterior is stripped away, is revealed to be a hero.



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Ford, still strapping at 67, isn't battling intergalactic bad guys, indigenous warriors, or even his own demons this go-around. His current alter ego, the cranky but brilliant scientist Robert Stonehill, is at war with a rare genetic disorder called Pompe (pronounced pom-pay) disease.

This debilitating condition affects about one in 40,000 people worldwide, many of them infants and young children, in the cruelest of ways. It leads to severe muscle weakness, rendering its young patients weak, wheelchair-bound, and fighting for breath, with enlarged hearts and livers. Pompe disease is a certain death sentence without treatment, which, until recently, didn't exist.

Cut to our action hero—or, in this case, maybe it's more accurate to say *action heroes*—to save the day.

The movie, which opens nationwide on Jan. 22, is inspired by the remarkable true tale of John and Aileen Crowley and their three children. The youngest two—Megan and Patrick—were diagnosed in 1998 with Pompe disease at ages 15 months and 5 months, respectively. With both Crowleys unknowingly carrying a copy of the recessive Pompe mutated gene, the couple had a 25% chance of conceiving a child with

the condition and a 50% chance the child would become a carrier. But it took Megan falling behind developmentally before she—and the entire family—was tested.

These desperate parents were willing to do anything to save their kids, even if that meant John Crowley's quitting a job with good health insurance to raise funds for experimental research, and then launching his own biotech firm to bring a promising new Pompe therapy to medical trial. Ford's Stonehill character is a composite based on several actual scientists with groundbreaking ideas; in the film he becomes, as Ford puts it, the unlikely "foil and partner" to one very determined dad.

"John sought out and reviewed all the available information about the disease," Ford tells WebMD from his office at the small, relatively sleepy Santa Monica Airport. "He decided that [backing one researcher's work] was his best shot to bring a drug quickly to the marketplace ...

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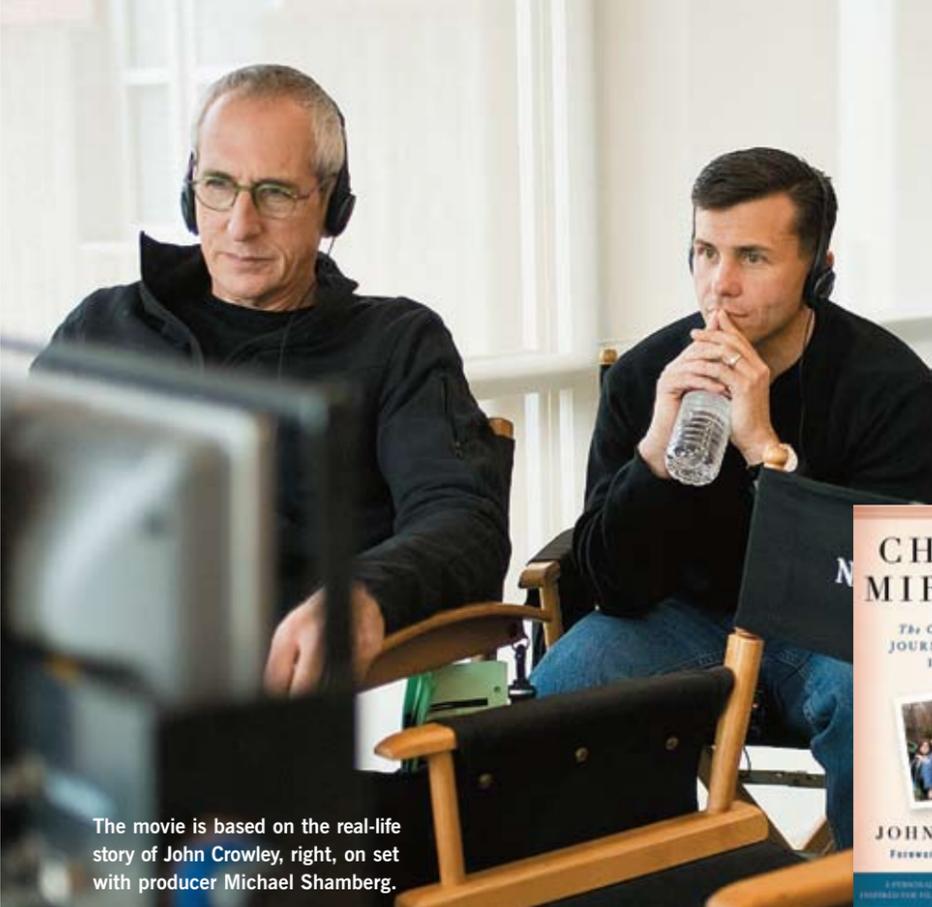
but he found out there were many, many obstacles before he could do so."

Medicine Man

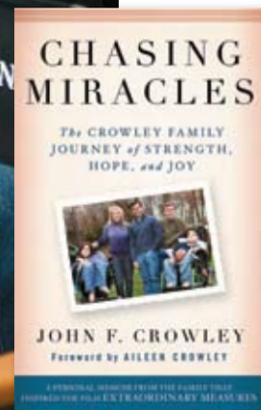
The real-life John Crowley has garnered ample media attention for the extraordinary measures he took to cheat death's grip. *Wall Street Journal* reporter Geeta Anand chronicled his mission in a 2003 article she later expanded into the book, *The Cure: How a Father Raised \$100 Million—and Bucked the Medical Establishment—in a Quest to Save His Children*.

Ford, who in addition to starring in the film served as its executive producer, felt the story was intensely compelling. "A father who gives up so much of his life to devote himself to finding a cure for what ails his kids is something I was attracted to. But I was also attracted to the elements of the story showing the difficulty of bringing a drug to market."

To deliver such a drug Crowley found himself working against a ticking clock.



The movie is based on the real-life story of John Crowley, right, on set with producer Michael Shamberg.



reel life—Crowley ran out of money. He was forced to sell his fledgling company to a bigger biotech firm, Genzyme, whose leaders welcomed his continued management of his research team.

Then came another blow. When Genzyme eventually developed a treatment for Pompe, his kids "were rejected to be part of the original drug trials because of conflict of interest," Ford says.

"That was more than frustrating," Crowley was quoted as saying in 2007. "Even though the FDA was comfortable with Megan and Patrick being part of the trial, the hospital's Internal Review Board rejected their application" because he was an executive of the company. "So I made it easy for them," he says. "I promptly quit my job." (Spoiler alert: In the film—most likely for added dramatic tension—he's fired.)

This third-act setback does lead to a happy ending, however.

Ford and Brendan Fraser team up to find a cure for Pompe disease in *Extraordinary Measures*, opening Jan. 22.



The life expectancy of Pompe patients diagnosed as infants is, at most, nine years, although most children die within the first year of birth from heart or respiratory complications. He knew the secret to creating a treatment in time for Megan and Patrick, who were growing weaker by the day, would be found among academic researchers with cutting-edge—if seriously underfunded—theories. "Failure wasn't an option," the real Crowley tells WebMD.

Ford acts opposite Brendan Fraser and Keri Russell, who play the Crowleys, but science is the real star here. "People with Pompe disease are missing an enzyme in their cells that breaks down glycogen [a storage form of glucose, or sugar]," says Hung Do, senior director of the Discovery Biology department at Amicus Therapeutics. Do, who has a PhD in medical biochemistry and genetics, served as the official scientific adviser to the film—and was one of the original members of the research team on which Crowley gambled. "All that

glycogen builds up within the body's cells and leads to the many biochemical and physical problems associated with the disease."

Enzyme replacement—a therapy that delivers the missing enzyme into the body's cells, thus enabling the drug to break down glycogen and allow cells to function normally—was the goal. "But getting the enzyme inside the cell to the proper internal location is difficult," says Do. "You've got to deliver the enzyme with the proper packaging—wrap it with a bow, if you will—in a way that a cell agrees to accept the enzyme. And that's what our research focused on."

Mission Nearly Impossible

"I knew nothing about any of this when I first started," Crowley says. "Once the seed money was in place and the science [to develop an effective enzyme therapy] was down, my initial foray into the biotech industry was two steps forward, one step back. But I think my 'never quit' attitude made up for my lack of experience."

Clearly. As the film movingly depicts, developing a therapy from the innovative thinking of scientists—represented by Ford's character—was merely step one. Just as progress was being made—in real and

ILL Advice

When your child gets a serious diagnosis

It's every parent's worst nightmare: Like the Crowleys' kids, your child has been diagnosed with a serious illness. How do you secure the very best care while keeping your home front—not to mention your emotions—intact? Carla Oliver, MSW, CCLS, manager of the Therapeutic Recreation/Child Life Department at the Children's Hospital in Aurora, Colo., offers these tips:

▶ **Pick the right hospital.** Check up on a hospital before sending your child there, says Oliver. "The Joint Commission (www.jointcommission.org) is an agency that is basically the 'police' of hospitals. Its staff randomly shows up at hospitals and either gives accreditation—or doesn't. Also, you can find out what other doctors have to say about specific hospitals." Harvard Medical School's national hospital rating system (www.health.harvard.edu) is another good resource.

▶ **Partner with your doctor.** Find a pediatric hospital that embraces a "family-centered care philosophy," Oliver advises. "Not all do. This basically means that the family of the child is the expert ... they are in collaboration with their doctors. A lot of the time Mom really does know best."

▶ **Educate yourself.** Nearly all U.S. pediatric hospitals employ at least one child life specialist, a health care professional trained to guide parents and their kids through upcoming medical procedures and the recovery, says Oliver. But parents should also arm themselves with the facts and challenges of their child's condition.—LPK



Great Outdoors

Ford fights for nature's medicine cabinet

Harrison Ford, a committed environmentalist, wants us all to understand the connection between endangered ecosystems and our own health. Open your medicine cabinet and it's likely that many of the medications your family relies on were originally derived from plants and animals, some of them already threatened in the wild. Ford serves on the board of Conservation International (www.conservation.org), which works with indigenous communities around the world to help preserve natural habitats including rain forests and coral reefs teeming with life—and current (and potential) medical treatments.

The organization's health security adviser, Judy Mills, says, "Some of the most innovative leads for Alzheimer's and HIV/AIDS, and new antibiotics for infectious diseases—to name just a few—are all coming from threatened ecosystems. And we don't know what's coming down the pike. We could be destroying potential cures for diseases we don't even know about yet." Mills adds:

► **More than 50%** of modern, or "Western," medicines were initially derived from plants or animals. A few examples: **Aspirin** came from the bark of the willow tree. The cancer drug **Taxol**, used to treat breast, lung, and ovarian cancer, was created from the endangered Pacific yew plant. The active ingredient **warfarin**, derived from sweet clover, is a treatment for blood clots. The powerful painkiller **Prialt**, given to patients who cannot tolerate morphine, comes from the sea's cone snail. And **drugs to treat childhood leukemia** are found in the rosy periwinkle.

► **More than 90%** of traditional medicines—ancient cures from China, Japan, Korea, plus Tibetan Unani and Ayurvedic treatments—come from plants and animals. These include **ginseng** for combating fatigue and stress as well as symptoms associated with type 2 diabetes. **Bear bile** has long been used to treat gallstones, hepatitis, and liver disease. Chinese **Artemisia**, a plant traditionally administered to fight fever and parasitic infections, is the main source for the new drug Coartem for cerebral malaria; it is expected to save more than 600,000 lives this year.—LPK

Free from Genzyme's constraints, Crowley's children received their first enzyme infusions in January 2003. While the stages of their illness were too far advanced to bring about complete recovery—recent studies show infants receiving the therapy lead nearly normal lives—both Crowley kids immediately improved. Megan's enlarged heart returned to its normal size within six months of getting that first dose. Patrick, too, gained strength.

Seven years on, they are relatively healthy and, most important, alive. And they consider their father—whose memoir about the experience, *Chasing Miracles: The Crowley Family Journey of Strength, Hope, and Joy*, is due out in January—a true action hero.

Taking Flight

Just don't call Ford that—at least not to his face. The "action star" moniker, he thinks, comes from "my films that have made the most money. But [those who elevate him to such status] are not relating to my whole body of work." Even if Ford's biggest parts admittedly do involve light sabers, swords, or the occasional bullwhip, his protagonists are, without exception, "in way over their heads," he insists. He sees himself as a character actor who just happens to be a leading man. *Extraordinary Measures* included, he gravitates to plum roles that reveal "a path of development ... I'm not a professional showoff. I'm a storyteller."

But if acting is all about taking action, look no further. Ford has never rested on his Han Solo-Indiana Jones-Jack Ryan laurels. He challenges himself. Here at the Santa Monica Airport, he houses three of his own small planes and a helicopter.

"Around 14 years ago, I realized I hadn't learned anything new in a very long time," he says.

"I wanted to learn how to fly: the skill of it all, the interface between responsibility and the freedom it grants you. It reinvented the world for me, and how I answer the question, 'What do you do?' Well, I now can say 'pilot.'"

These days, when Ford isn't busy searching for the next great script, he's hanging out in remote northern Idaho with his flying buddies.

"We set up a camp in one of these wilderness strips," he says, "and each day we break up into five or six flights and land



Ford with fiancée Calista Flockhart and her son, Liam, left.



Does this longtime champion of the environment see progress? "There have been small victories. We need a groundswell, to the point where the moral authority of it becomes so obvious that this is what we need to do."

in challenging places. It's beautiful, but it's about practicing, about what gets you safely up and down."

Ford also regularly flies between Los Angeles and his home in Jackson Hole, Wyo., one of several residences he shares with his fiancée, actor Calista Flockhart, and her son, Liam, 9. The actor also has four grown children—Benjamin, Willard, Malcolm, and Georgia—from two previous marriages.

Environmental Agent

Ford takes action in other ways, too. His commitment to environmental issues is long-standing, from humorous public service announcements where he waxes his chest hair (ouch) to illustrate deforestation to another PR push to help save endangered tigers.

And he puts his money where his mouth is. A board member of the environmental group Conservation International for nearly 20 years, this former Boy Scout "always loved nature. But once I made some money"—in 2009, *Forbes* magazine ranked him as the wealthiest actor in

Hollywood—"I was looking to use it to have an effect. Money can buy science in support of conservation. It can teach indigenous people politics or a fisherman some other task when the fisheries he uses are overburdened."

Does this activist see progress being made in the protection of rainforests and coral reefs as the environmental movement's top priority? "There are a million little fights all coming together in one big battle," Ford answers passionately. "And there have been small victories. But not the big battle, not yet."

"We need a groundswell, to the point where the moral authority of it becomes so obvious that this is what we need to do."

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