

# Rotary

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MAGAZINE

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## MATERNAL AND CHILD HEALTH

# A solution hiding in plain sight

*Inexpensive vitamin B9 can prevent spina bifida. Why are thousands born each year with the condition?*

**T**he highlands of Ethiopia are filled with lentil farms. It's a mighty legume rich in the natural form of folate, a vitamin recommended for women who can become pregnant to help prevent congenital defects that result in lifelong medical problems or even death.

And yet, when Patricia O'Neill and her late husband, Marinus "Dick" Koning, traveled from their home in Bend, Oregon, to Ethiopia for a humanitarian visit several years ago, they encountered people who had no idea. In one emotional exchange, a farmer told them he wasn't aware that the neural tube disorder his child was born with might have been caused by a lack of folate, a substance in the lentils he sold.

"He was just heartbroken," recalls O'Neill, president of the ReachAnother Foundation, a philanthropic organization focused on treating and preventing neural tube defects in children, including spina bifida. She and Koning, who was a surgeon and member of the Rotary Club of Redmond, Oregon, founded the organization in 2009 after an earlier visit to Ethiopia. "People first have to be aware of the problem, and then understand there is a solution to the problem — and that it's not just treatment, it's also prevention," O'Neill says.

Every year, more than 300,000 children worldwide are born with neural tube defects, such as spina bifida, when the spine fails to form properly in the first month of pregnancy. Another defect, hydrocephalus, involves a buildup of fluid in the

brain. Both are treatable but often cause serious impairments and require complex, lifelong care. And the condition anencephaly is an untreatable, fatal brain defect. Most of these cases could be prevented with folic acid, the synthetic form of folate. (Folate is also known as vitamin B9.) People need enough folic acid in their bodies before or shortly after becoming pregnant to help prevent these conditions at birth, and they can get the necessary amount through a dietary supplement or fortified food staples.

Ethiopia is particularly affected: More than 25,000 babies are born there each year with neural tube defects. About 80 percent of women of childbearing age in the country had blood folate concentrations low enough to cause a risk of birth defects if they had a baby, according to a recent study.

A growing number of Rotary members are working to change that. Their mission is to educate people around the world about folic acid, connect with policymakers to advocate for fortification of foods with the micronutrient (as some countries, including the United States, have done for decades), and help affected children get medical help.

Children born with severe cases of spina bifida, for example, often need multiple surgeries throughout their lives. They may have problems walking, have seizures, or require catheters. "And it doesn't go away," says Jogi Pattisapu, a retired pediatric neurosurgeon based in Orlando, Florida, and member of the Rotary Club of Lake Nona. "It's not like

Visit [rotary.org/our-causes](https://rotary.org/our-causes) to learn more about Rotary's work in maternal and child health and get involved.



By comparison, one case in the U.S. will cost a lifetime of care, in excess of a million dollars.”

Given the vastness of Rotary’s network and the generosity of its members, Peeler and others are hopeful that preventing more of these birth defects is within reach. “It’s almost a moral imperative, isn’t it? I mean, we have to do it,” says Jonathan Yaeger, also a member of the North Atlanta club.

With the help of a Rotary Foundation global grant, a project in Addis Ababa, Ethiopia, is underway to provide folic acid supplementation to women who have already had a child with a neural tube defect. Compared to the general population, these women are at a significantly higher risk for a future pregnancy to be affected, and a high dose of the vitamin has been shown to reduce the chance of a neural tube defect in children born later. The project is a partnership between the Rotary clubs of North Atlanta and Addis Ababa-West.

Meanwhile, in India, another global grant is helping pay for children to receive spinal surgeries and aftercare, says Els Reynaers Kini, a member of the Rotary Club of Mumbai Sobo. Parents, especially in rural

somebody broke their leg and you fixed it. It’s unfortunately an ongoing, revolving door of issues.”

But those medical complications are only a shadow of the problem, explains Yakob Ahmed, a Rotarian in Ethiopia and country director of ReachAnother Foundation. Other pregnancies end in miscarriage or stillbirth, or are terminated when neural tube defects are identified prenatally. All of the outcomes have

implications not only for the children who deal with them directly but for their parents too. “So you can imagine the scale of this problem globally,” Ahmed says.

Preventing the problem, whether through vitamin supplements or food fortification, is affordable, says Ralph Peeler, a retired physician and member of the Rotary Club of North Atlanta. “It costs a few cents per person [per year] to fortify food.

**Top:** The Rotary Club of Visakhapatnam, India, co-hosts a spina bifida seminar for aspiring medical students. **Below:** A shipment of folic acid arrives in Ethiopia for a global grant-supported project.



BY THE NUMBERS

300,000

Number of children born each year with neural tube defects

1 in 100

Prevalence in low- and middle-income countries

80%

Portion of women of childbearing age in Ethiopia with folate deficiency

areas, often don't know how to help a child born with spina bifida and lack critical support, she says. "So they're not necessarily investing much in these children. As a result, typically these children don't go to school. They're being sidelined," she says.

In Colombia, Sonia Uribe, a member of the Rotary Club of Nuevo Medellín, is director of Fundación Mónica Uribe por Amor, which helps children with spina bifida. The foundation also developed a campaign with support from Rotary clubs to educate teenage girls about folate and good sources of it, including lentils, peas, and broccoli.

But perhaps the most impactful frontier is fortifying the food supply in more countries. Enriched foods, from breads to cereals and more, make it easy for many people to get the vitamin, helping ensure women have enough early in pregnancy to guard against birth defects. The World Health Organization passed a resolution last year recommending folate fortification. "One of

the most equitable interventions that one can do is to put folate in something everybody eats," says Godfrey Oakley, director of the Center for Spina Bifida Prevention at Emory University's Rollins School of Public Health and member of the Rotary Club of North Atlanta.

In the 1990s, Oakley was instrumental in the effort to fortify foods with folate in the United States, while supervising the birth defects division of the U.S. Centers for Disease Control and Prevention. Eighty other countries are also fortifying cereal grains with folate. Yet more than 100 countries still don't have folate fortification programs, for reasons ranging from a lack of political will and concerns from the food industry to competing public health priorities. Oakley and others are hopeful Rotary's web of connections can help raise awareness and motivate policymakers to take action on fortification.

It's been more than 30 years since a pivotal trial showed unequivocally

that taking folic acid starting before pregnancy can prevent most cases of neural tube defects. The failure of so many countries to require mandatory fortification is a tragic missed opportunity, says Victor Hoffbrand, author of the book *The Folate Story: A Vitamin Under the Microscope*.

Over the years, science has shown fortifying foods is safe, he says. What's more, it not only reduces birth defects but also combats a type of anemia that affects men and women. "The hope is that there will be universal fortification for every country," Hoffbrand says.

As Rotary continues its efforts, neural tube defects have the potential to become much rarer than they are today, Rotarians say. "This is about healthy kids and having maternal and child health," O'Neill says. When family members are healthy, it also puts less financial strain on caregivers and contributes to a productive workforce overall, she notes. "I don't see how that can't be a win-win." — AMY HOAK

Jennifer Jones, 2022-23 Rotary president, (center) visits Fundación Mónica Uribe por Amor in Colombia in 2023 with current RI Vice President Pat Merryweather-Arges (left) and Past RI Director Suzi Howe. The foundation helps people with spina bifida.

Short takes

Past RI President Jennifer Jones promoted the Global Polio Eradication Initiative in a video shown at the Global Citizen Festival in New York in September.



For World Mental Health Day, 10 October, Rotary organized a discussion on prioritizing mental health with RI President Gordon McInally and advisers. Watch it at [on.rotary.org/10oct-yt](https://on.rotary.org/10oct-yt).