THOMAS PRIOR

Who gets to say when unproven therapies can be offered to desperate people? To some, it's a matter of life or death. **Peter Aldhous** talks to the...

Stem cell crusaders

THIS article began life last September, when an accusatory email landed in my inbox. It had come from SammyJo Wilkinson, a former internet entrepreneur in her late 40s, who lives in Seattle with her husband. Two decades after being diagnosed with multiple sclerosis, Wilkinson (pictured), is fighting a medical establishment that she reckons is thwarting her only chance of an effective therapy.

"We have a right to obtain these treatments and pieces like yours, that lack balance, will reduce our access," she wrote. "Your pieces are all written from the perspective of scientists with financial conflicts of interest."

The email left me a little piqued, I must admit, but also intrigued. I'm used to the idea that scientists aren't all angels, having reported on research misconduct in the past, from image doctoring to wholesale data fabrication. Still, I didn't recognise this picture of a conspiracy suppressing people's only chance of a cure.

OK, I said to Wilkinson, let's talk.

The therapies in question involve stem cells, routinely touted as the solution to many of the diseases that blight our lives. Just when this new era will arrive, however, is unclear, as the field is still in its infancy.

Despite the uncertainty, Wilkinson and others with similarly debilitating illnesses want to forge ahead with treatments using stem cells taken from their own bodies. Their problem is that the US Food and Drug Administration says that, under certain circumstances, such remedies are classed as drugs – which means they must first undergo a lengthy testing and approval process.

The row came to a head last September, when the FDA shut down a firm in Texas that was bringing hundreds of patients like Wilkinson the treatment they desired. Given the growing numbers of clinics around the world charging many thousands of dollars for unproven stem cell "cures", it is easy to view the FDA's move as part of an essential clampdown. But after lengthy conversations with Wilkinson and other activists, I've come to see that the picture is more complex than it first appears.

Wilkinson put me in contact with a small but highly vocal group of activists who organise online through websites like Patients for Stem Cells. Their medical conditions differed but all had reached the limits of what orthodox treatments could offer them and saw stem cells as their only hope.

So what exactly are stem cells? Unlike most of the cells in our bodies, which have a finite lifespan, stem cells can keep dividing and replenishing themselves. They can also give rise to a variety of different specialised cell types – hence the optimism that one day they might be able to treat a whole range of conditions, from heart attacks to Parkinson's disease, and diabetes to spinal cord injuries.

Embryonic stem cells, obtained from developing embryos a few days after fertilisation, can produce all the cells in the human body (see "Cell sources", page 44). Our bodies also contain small numbers of adult stem cells, which give rise to a narrower range of cell types, and normally help to maintain and repair our tissues. These include mesenchymal stem cells, or MSCs – the cells in which Wilkinson has placed her hopes.

Found in bone marrow and certain other tissues, MSCs build bone, cartilage and fat. But it has recently emerged that these cells have another crucial property: they respond to injury and inflammation by releasing signalling molecules that can promote healing and damp down unhelpful immune reactions. "You need to think of MSCs not as stem cells but as drug factories," Arnold Caplan, who studies the cells at Case Western Reserve University in Cleveland, Ohio, told me.

Out of time

Most stem cell treatments are years away from routine use. But those based on MSCs have advanced further. For instance, a treatment to promote healing in cardiac muscle after heart attacks was approved in South Korea in 2011. And dozens of trials are under way, using MSCs in a wide variety of diseases, including Wilkinson's condition, multiple sclerosis.

People like Wilkinson feel they do not have time to wait for these trials to complete. And they are wary of efforts by the International Society for Stem Cell Research to warn people away from accessing unapproved stem cell treatments. They think the society's researchers are acting to protect their own financial interests in rival stem cell therapies that are years away from fruition.

This view was expressed to me most ›