

# Taking up the Challenge of Creating an Inclusive Society from the Field of Regenerative Medicine

## From the Tangible to the Intangible: Redefining Medicine as People-centric

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Graduated from the Faculty of Medicine at Kyoto University in 1986 and obtained a PhD from the Graduate School of Medicine at the same university in 1992. After working in an assistant professor, also at the Kyoto University Faculty of Medicine, she took up a research role at the Salk Institute for Biological Studies in 1995. She discovered the potential for using stem cells in retinal therapy. In 2006, she moved to the Institute of Physical and Chemical Research (RIKEN). She embarked upon clinical research into the transplantation of sheets of retinal pigment epithelial cells derived from the patient's own iPS cells to treat exudative age-related macular degeneration, with the first such transplantation taking place in September 2014. A transplantation of a suspension of retinal pigment epithelial cells derived from donor iPS cells was undertaken in March 2017. She took up her current position in August 2019.

### What Makes a Society Inclusive?

Inclusiveness has come to be one of the ideals to which society should aspire. This term, which is heard frequently these days and carries meanings of being comprehensive and all-encompassing, is used to indicate a state in which everyone is respected and embraced as a member of society, without being excluded on the basis of any particular personal attribute, whether gender, race, social or economic status, or whether or not they have a disability. In other words, an inclusive society can also be described as one where people coexist in harmony.

In this article, I will draw on what I have seen in my work on the therapeutic development of retinal regeneration to discuss the challenges to achieving an inclusive society and what will help us overcome them. In doing so, I hope I can aid progress toward this goal.

### Regenerative Medicine and the Requirements of Whole-person Care

As well as practicing as an ophthalmologist, I have been engaged in research into retinal regeneration for more than 20 years. As eye health can be affected by a number of difficult conditions, including both degenerative and hereditary disease, I have been motivated by a desire to do what I can to improve the lives of the patients I see.

A major step forward in this research into the development of new therapies and their clinical application came in 2014 with the successful transplantation of retinal cell sheets derived from the patient's own induced pluripotent stem (iPS) cells (a world-first for the clinical use of iPS cells), followed subsequently by the transplantation of donor iPS cells, which was also successful. (Of note is that the automatic cell culturing system used for the cell sheets was provided by Hitachi.)

Another area that I think is just as important as the field of regenerative medicine is that of low vision care. This is the assistance provided to people who face difficulties in going about their lives due to impaired vision and covers a wide variety of different forms of support, from medical care to educational, vocational, social, welfare, and psychological care.

One feature of eye diseases is that they are accompanied by a high level of social anxiety due to people's fears for what sort of life they will be able to lead if the progression of their disease leads to a significant loss of vision. Misunderstandings encouraged by inadequate or misleading information result in a significant number of people giving up on life or becoming socially withdrawn. A wide variety of care is publicly available, as already noted, and not only does this allow people with eye diseases to go on living in the community, it also inspires hope for their own future when they learn how many other people in similar situations remain active participants in society.

This situation was powerfully brought home to me by my experiences at a specialist outpatient facility for people with serious retinal disease who are candidates for regenerative medicine. Treatment based on medical technology on its own is not enough to make patients' lives better. Rather, what is needed is whole-person care that is in touch with the patient's feelings and covers both mind and body, not least of which is the provision of reliable information on living in the community.

This is true not only of ophthalmology, and in the emerging future of diagnosis by artificial intelligence (AI) and surgery by robot, providing this whole-person care will be the most important role that still remains for human medical staff to play.

As noted above, regenerative medicine is only now beginning to be used in practice and is currently at the stage of demonstrating safety, which includes demonstrating that it does not result in tumors and that tissue rejection can be controlled. Unfortunately, it is not yet able to deliver the dramatic cures such as a full restoration of function that many people are hoping for. Accordingly, there is a need for low vision care in such forms as postoperative rehabilitation, training in the use of digital devices and other aids that make the most of the small recovery in visual function, and support for a return to work or study, with regenerative medicine and whole-person low vision care needing to be developed in tandem.

The Kobe Eye Center was established in 2017 on the basis of this philosophy, prompted also by the high level of interest in the clinical research of iPS cells described above. One of the few such centers anywhere in the world to combine facilities that encompass research, therapy development, ophthalmological medicine, rehabilitation, and support for returning to the community, its aim is to overcome the challenges of visual impairment by whatever means possible.

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## **Public Disconnect Preventing an Inclusive Society, and How to Overcome it**

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What is important when seeking to achieve whole-person care is not only the care provided to the patients themselves, but also the building of livable communities in which all people who have impaired vision can feel confident about participating and going about their lives. This means there is a need for change, starting with the attitudes and rules of an inclusive society. One step toward this is to establish an accurate recognition and understanding of people with disabilities. This is because there is an astonishing level of public ignorance about these people. Vision impairment, for example, comes in gradations of varying severity, not only total blindness, with significant variations in people's vision. Meanwhile, many of the people who suffer from "low vision" rather than blindness (meaning those in the low to medium range of severity who make up the largest proportion of the vision impaired) draw on their exceptional talents or various aids to work alongside us in the corporate world, and yet, despite contributing to society in this way, their existence goes largely unrecognized. Among the reasons for this is a desire to keep their disability hidden out of fear that being seen as disabled will put them

at a disadvantage or expose them to unreasonable discrimination born out of a lack of understanding.

Providing the public with accurate information about these people's undercover existence is both the responsibility and duty of those who work in the field of ophthalmology and understand their situation. What exactly is vision impairment? What sort of lives are lived by those who suffer from it? We are currently running a public campaign called the I See! Movement aimed at publicizing the true predicament of the vision impaired.

What is it then that makes the existence of these people so hard to recognize? The answer is the more deep-rooted problem that the public tend to compartmentalize people into being either able-bodied or disabled (severely vision impaired). Although impairment comes in a wide range of severities, social welfare has traditionally focused exclusively on the severely disabled and made them the sole target of protection and assistance. Somewhat paradoxically in this regard, society meanwhile has been put together in a way that focuses entirely on the able-bodied, as if disabled people do not exist. This has resulted not only in the many partially disabled people who fall between these two extremes being overlooked, but also in the emergence of a deep gap in between that has caused a disconnection in society. The aforementioned social anxiety experienced by patients who suffer from difficult-to-treat eye diseases is due to their perception of their situation brought about by this disconnection between the disabled and the able-bodied that relocates them into an entirely different world, the one inhabited by the disabled. If we continue in this manner, then we will be unlikely ever to fill in this gap, however much we may plead for an inclusive society.

The way to resolve this problem is to bring about a small shift in the center of gravity of society, which in the past has been assumed to reside with the able-bodied, relocating it somewhere in between, which is to say, in the region occupied by those with light to moderate impairment. Recognizing that everyone possesses some form of disability, some imperfection or weakness, placing the disabled at the center of society on the basis that some impairment or difference always exists will naturally foster continuity across society, bringing the two extremes closer together. This is something that is desirable for both sides.

For example, people who to date have been considered able-bodied will gain peace of mind by being freed from the compulsion of having to follow what is sanctioned as acceptable by society in terms of being healthy or normal. A society that supports people in living their lives how they want regardless of whether or not they have a disability should be an easier place to live for everyone, not just those with disabilities.

Rather than being about acceptance of the disabled, surely a truly inclusive society is one where people coexist and recognize each other's differences.

The key to encouraging a change toward such a society is the concept of "barrier value." This is the idea that the differences and alternative perspectives represented by a disability (barrier) offer new insights or value that overturn accepted wisdom. The way I express this to others is to point out that a failure to appreciate the disabled is a loss, as is a failure to look at society in inclusive terms. In fact, I believe that everyone has such value and is able to contribute. Moves are also underway to turn barrier value into a business to help the public at large take this idea on board.

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### Development of Regenerative Medical Practices that Go Beyond Existing Bounds

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Developing therapies based on regenerative medicine, complementing these with low vision care, and putting in place the institutions of an inclusive society: the therapeutic development of regenerative medicine encompasses all of these challenges. They are what it means, in other words, to put regenerative medicine into practice.

I have already touched on how post-treatment whole-person care is vital for the early techniques of regenerative medicine, which are still in the development phase. Moreover, because regenerative medicine involves the use of cells, its efficacy is variable like that of Chinese medicine rather than delivering uniformly predictable results as is expected from Western medicines. As this inevitably makes it necessary for therapy to be customized to offer the mix of treatments and care that best suits each individual, the therapeutic development of regenerative medicine calls for healthcare in the original sense of changing the patient's circumstances so that they can live a better life. In this sense, it is fundamentally different than the way in which therapies have traditionally been developed.

I have refocused my efforts several times in the past in order to facilitate this therapeutic development. Transferring from Kyoto University to the Institute of Physical and Chemical Research (RIKEN), subsequently getting fully involved with the business side of things with the establishment of the Vision Care medical venture 2019. This is simply a case of establishing a position from which, as well as being a link between organizations, I have the freedom to move ahead with what is needed for therapeutic development, things that I would have been unable to do from within the bounds of academia. It includes the deployment of therapies that use iPS cells and

the commercialization of "barrier value."

To achieve such a major goal, it is important not to be shackled by the limitations of your particular organization or field. Rather, taking a step back to obtain a better angle that offers a broad view encompassing adjacent fields also provides you with additional information, giving you the leeway to come to grips with solving problems in ways that had not previously been evident.

Even though numerous organizations and facilities for the care of the vision impaired existed in Kobe prior to the establishment of the Kobe Eye Center, there was little coordination between them. By providing a more elevated perspective and serving as a common point of public access for overcoming the challenges of vision impairment in various different ways, it has enabled these organizations to work together based on mutual understanding of their respective activities, and more recently has even brought in new partners who can help achieve the goals.

Likewise, the Vision Park at the entrance to the center is the result of a multidisciplinary collaborative effort involving not only ophthalmologists, but also architects, furniture designers, and acoustic designers. Like the public space it is, the park has been created as a hub for the presentation of information that will transform attitudes toward vision impairment, providing a natural venue for the disabled and able-bodied to mingle.

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### Emulating Medicine's Responsibility for Fostering Public Wellbeing

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The public concept of value in various different areas is undergoing a transformation from the tangible to the intangible. As we have seen, the therapeutic development of regenerative medicine can be taken as a practical example of redefining the nature of healthcare away from tangible drugs and medical technology and toward the people-centric intangibles of whole-person care.

What I am conscious of in this transition is that it is not possible to change society by relying solely on medical technologies that produce tangible goods. If we are to seek out new societal practices and arrangements, and especially to consider the impacts of technology on people and the interaction between them, then it is also vital that we work in partnership with people from the humanities and social sciences who possess knowledge that encompasses people and society itself.

Meanwhile, viewing matters through this lens, I have come to see that the humanities also suffer from something that I have long pointed out as being an issue with Japanese science and technology, namely that while there is extensive basic research being done, the amount of applied and commercially

oriented research is very low compared to Europe and America. More crucial still is that the people involved have little awareness that this problem of an inadequate implementation process even exists. The ideas and concepts that you come up with may be wonderful, but it is irresponsible to leave it up to politicians or business people to put them into practice. I believe that everyone who is part of society has a responsibility to try and improve it, and that this is especially true for academics.

I believe the reason why I feel this way is because, as a doctor, I have a direct responsibility for the patients I see. One thing I have been reminded of recently is that medicine is an all-encompassing discipline spanning both the sciences and the humanities (society and people as well as science and technology).

This has been symbolically highlighted by the current pandemic. Many medical practitioners regularly post useful information on social media and I believe they do so from a sense of social responsibility that is characteristic of those who work in healthcare and takes the form of wanting to do what they can to help the people around them. In this, I am no exception. In my case, just as I am doing with regard to patients who suffer from eye diseases, I have wanted to help people who, in a situation that has come to be called an “infodemic,” have fallen victim to misleading information that is causing them anxiety, and by doing so get them back on the right track.

We now live at a time when our responsibility to make society better has a bearing on everything we do. It is already the case in many developed nations that companies that fail to embrace the Sustainable Development Goals (SDGs) are being shunned. While this may not be the only reason, it is likely that they understand that when their own interests and those of society overlap, it brings access to more assistance and investment, and that this is a source of enormous strength.

While Japan is unfortunately lagging in this area, striving to achieve balance in a way that considers what is best for society as well as for one’s self is something that Japanese people are naturally good at. An event that I hope will take advantage of this national character and seek to communicate new value out of Japan is the Osaka, Kansai Expo 2025. As indicated by



**Kobe Eye Center's Vision Park**



**Low Vision Care Workshop Held at Hitachi's Kyōsō-no-Mori Facility for Collaborative Creation**

its theme of “Designing Future Society for Our Lives,” rather than exhibiting tangible goods such as scientific technologies or buildings, it aims to present something more conceptual, namely the new social systems of the future. More specifically, it involves a fundamental reappraisal of the financial and shareholder capitalism of the past, aiming instead to present a vision of a society in which human wellbeing comes to be seen as the unit of currency that both serves as a measure of value and symbolizes what value is. Rather than profit maximization, I believe that putting the wellbeing of everyone at the heart of society will naturally result in the sort of inclusive society where everyone can pursue happiness in their own way, regardless of their personal attributes.

The Social Innovation Business of Hitachi represents the ultimate in intangible-building for creating the society of the future. Hitachi is already a trusted partner in regenerative medicine, but more than this, as one of the few organizations that understands and supports the true significance of barrier value, having taken the lead in areas like happiness research, I put my heartfelt trust in it as a partner for the collaborative creation of a genuinely inclusive society where people are central.