

Patient Groups and Stem Cell Research

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Hundreds, if not thousands, of patient groups have emerged around the world to help support the needs and interests of people living with a diverse range of medical conditions. Given that the needs of people with a given condition are often quite specific, many of these organisations focus on a single medical disease (for example, the American Diabetes Association, the Canadian Cancer Society and the Japan Spinal Cord Foundation), while others have a broader remit.

Many diseases such as diabetes, muscular dystrophy and cardiovascular disease, to name but a few, remain incurable or terminal but there is hope that, in the future, scientific research will lead to the discovery of new treatments or cures. In particular, there is significant hope that stem cell science will enable scientists to discover a way to 'regenerate' parts of the body, which have become damaged.

Given this potential of stem cell science to lead to cures for currently untreatable conditions, patient groups have played a key role in supporting research in this area and collaborating with scientists as well as policymakers to increase public funding for stem cell research as well as to reduce regulatory or legislative barriers. Unlike other stakeholders in these debates such as policymakers and scientists, patients can be particularly effective in swaying wider public opinion by making a compelling case for stem cell research based on their own personal testimony of living with a terminal or incurable condition.

Patient groups around the world are increasingly involved in debates around funding and regulating stem cell research, working to support stem cell research in three primary ways:

1. Lobbying politicians and government health agencies to remove what they view as overly strict regulations on stem cell research and clinical trials;
2. Promoting or increasing current levels of public funding for stem cell research on specific diseases;
3. Raising funds and sponsoring stem cell research for specific diseases.

Patient groups in the United States and Europe have been particularly involved in debates around the ethics of using discarded embryos for the purposes of stem cell research. In the US, patient organisations worked with commercial biotech companies such as Geron and Advanced Cell Technology to lobby for continued government funding for embryonic stem cell research (Taylor-Corbett 2000). Recently, patient groups based in Europe issued a joint statement with research funders to urge the European Parliament to continue funding embryonic stem cell research (EuroStemCell 2012).

Public debate on the ethics of embryonic stem cell research has been less contentious outside of Europe and North America. Nevertheless, as in Western countries, patient support groups in other contexts such as Asia also support and advocate for greater investment in stem cell research, particularly organisations focused on degenerative and incurable diseases. In Japan, for example, patient groups such as the Japan Spinal Cord Foundation in many Asian countries, for example, have worked with scientists to advocate for government funding for stem cell research (Sleeboom-Faulkner 2008). In India, where there is less government funding for stem cell research, patient groups have collaborated with commercial stem cell providers in enabling clinical research using stem cells for conditions such as muscular dystrophy (for example, through assistance in recruiting patients). There have also been reports of cases in which the families of individuals with incurable conditions such as spinal cord injury are working with stem cell scientists to fund clinical trials in private hospitals in India (Rao 2011).

Despite this range of activities, it remains the case that stem cell research is still only experimental. Clinical trials employing stem cell therapies are few and inaccessible to the overwhelming majority of patients. In low-income countries in which even basic needs of patients often remain unmet, patient groups continue to focus more heavily on support and care-giving activities rather than engaging in wider health policy advocacy for stem cell research.

Moreover, it is important to note that while in general patient groups are in favour of stem cell research, there remains variation in the level of support between different groups.¹

References

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¹ For example, in Canada groups such as the Parkinson's Society, the Muscular Dystrophy Association, and the Juvenile Diabetes Foundation have been more active in campaigning for stem cell research compared with groups such as the Canadian Cancer Society (Downey and Geransar 2008: 79).

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