



Privileged Embodiments: Securing and Resisting the
'Valuable' Body

PEALS Spring Symposium

21st and 22nd of March 2013

Great North Museum, Newcastle upon Tyne



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Must leave venue by 5pm

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<http://www.caffevivo.co.uk/>

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Symposium Abstracts

Edmund Coleman-Fountain and Janice McLaughlin

Re-shaping young disabled bodies: Exploring the implications of and reasons for different forms of medical and self-intervention

Children born with physical impairments can spend much of their childhood receiving medical procedures. In the case of cerebral palsy these procedures include multiple surgeries, wearing splints, regular physiotherapy and frequent injections of chemicals such as Botox. These interventions reshape the child's body, with the aim of minimising the impairment and improving mobility. They also bring with them scarring, pain and discomfort and significant disruption to children's everyday lives as hospital appointments and treatments take them out of school, away from friends and replace other forms of fun. The frequency of such interventions reduces as the child move towards adulthood. This does not mean that attempts to reshape the body end, but instead that the form of intervention may change. This paper explores the perspective of young people with cerebral palsy as they reflect back on childhood experiences of medical intervention and discuss present attempts to reshape their bodies through their own interventions. We discuss the different forms of emotional investment the young people place on their bodies through memory and current activity, situating that investment within their location as young disabled people seeking agency and normality in their imagined adult futures. We consider how this is influenced by a context where disability and forms of dependency are seen as troubling a key marker of adulthood – independence. The paper is drawn from an Economic Social Research Council study in the North of England, working with young people with cerebral palsy using qualitative methods including both interviewing and creative practice.

Cathrine Degnen and Monica Moreno Figueroa

Regarding beauty: Transnational understandings of the ageing body, beauty and emotions

Older age is a highly stigmatised aspect of the life course. Physical changes associated with older age are often the focus of this stigma, and are commonly understood to mask the inner, 'true' self inside. In contrast, conventional notions of beauty are simultaneously highly valorised and most often assumed to reside in younger bodies. Beauty is thus a concept applied to the young and not to the old almost by definition, often disregarded as banal or as a matter of commercialisation and consumption. This paper reflects on how our project, *Regarding Beauty*, queries such assumptions about both ageing and the work of beauty in everyday life; a constant - yet simultaneously dismissed and unremarked upon - concern in people's lives that needs to be taken seriously. Moreover, cultural approaches to the study of emotions and affect have insisted on their relevance for social interaction as well as for meaning making. Emotions, learnt and felt, are key for bonding subjects to social norms. In this paper we will discuss how *Regarding Beauty* aims to explore what bonds emotionally the lived experience of ageing to particular ideas about the body and its appearance; how does that bonding operate; and, more broadly, what do emotions do in the lived experience of ageing. Here we will draw on a pilot research piece that interviewed 8 women, 4 British women and men and with 4 Mexican women developed to ground the larger research proposal. The discussion will explore, firstly, why would it be relevant to investigate the relationships between beauty, emotions and perspectives on the body (crucial to the quality of everyday life) amongst people in their 70s, 80s and 90s living in the UK and Mexico; and secondly, how do we aim to generate a groundbreaking methodological research process that explores through novel visual and material strategies how older women and men experience beauty as a series of *inescapable* processes and practices; how time inflects these experiences; and what

emotional investments and attachments are set in motion in the labour of 'looking one's best'.

Jacqueline Donachie

El Mal; artworks made around my sister and the scientists who research her

This presentation will focus on my own contemporary art practice, which uses research led processes and scientific collaboration to challenge and illuminate representations of experience in the fields of genetics, social science and contemporary art.

Several works explore the portrayal of those affected by the genetic disorder myotonic dystrophy (DM), particularly members of my own family. Self-ethnography informs this as I consider my position as the unaffected sibling, both within an affected family, and also within the world of scientific research, as international critical review of previous works demonstrates the capacity this practice has to collaborate and influence across disciplines.

'I stare at a picture of my sister's eyes; beautiful hazel eyes with very fine stitches from a recent operation to stop her eyelids dropping, another effect of the genes she has inherited. The myotonic dystrophy which she has inherited from our father causes progressive muscle deterioration, and her face is gradually changing as her muscles slacken and fail. She is 42, I am 39. We used to look alike. Now, not so much. We both have children; her son and daughter are affected by a more severe form of the gene, my three sons are not. We have several cousins also affected, and one in particular, a young woman, is desperate to start a family of her own. She knows the risks involved with this through the inheritance patterns of the disease, clearly visible in her cousin, my sister's, children. Appearance and reproduction are significant factors in how we, as women, deal with this; our family inheritance looms heavily above us. We carry a strong family resemblance, and as we age, I wonder when the illness will overtake these familial characteristics.

When will I become the only one who looks like we were all supposed to? *

* from *El Mal*; Jacqueline Donachie 2008. Catalogue text, exhibition publication *Talkin Loud and Sayin Something, Four perspectives on artistic research*. Gothenberg Art Museum, Gothenberg. Pub by Art Monitor, University of Gothenberg, 2008

Erica Haines

Like juggling on a rollercoaster? Gains, loss and uncertainties in IVF patients' accounts of volunteering for a U.K. 'egg sharing for research' scheme

The past decade has seen a growth in demand for human eggs for stem cell related research and, more recently, for mitochondrial research. That demand has been accompanied by global debates over whether women should be encouraged, by offers of payments, in cash or kind, to provide eggs. Few of these debates have been informed by empirical evidence, let alone by the views of women themselves. The research reported in this presentation addresses that gap in knowledge. I shall outline key findings from a UK investigation which is the first systematic study of women volunteering to provide eggs under such circumstances. I shall focus on the views and experiences of IVF patients who volunteered for the Newcastle 'egg sharing for

research' scheme (NESR), in which they could access cheaper IVF treatment if they provided eggs for somatic cell nuclear transfer research.

Bill Hughes

Classical embodiment and the invalidation of disability in ancient Greece and Rome

A compelling clue to the social and political dislocation of disability from the core community in Greece and Rome is manifest in a claim made by Herodotus, the father of history. He argues that the first and foremost qualification for human happiness lies in 'freedom from deformity'. The good life – *eudaimonia* - and disability are incompatible; an unruly physical or mental constitution cannot be reconciled with political or ontological integrity. Disabled people have no route to a full and happy life because, in Graeco-Roman culture, this depends on 'a sound body in a sound mind', on what the Greeks called *arete*. It is the template of virtue, visibly absent from the lives of disabled people and to be without it is to be in a struggle to be included, not just in the political and social community but – ontologically - in the club of humanity. I will argue that *Arete* – as the byword for privileged embodiment - establishes the moral grammar of ablesim in antiquity. In vitiating disability, *arete* legitimates an anthropoemic approach to impairment. Extermination and excommunication, therefore, constitute the standard forms of the disposal of disability in Graeco-Roman culture.

Jackie Leach Scully

Bionic betterment: prostheses, implants, and the right kind of disabled body

Disabled people commonly use a variety of assistive devices to do things that their impairment would otherwise prevent. These range in technological complexity from the very simple (eg canes) through more complicated (manual wheelchairs) to highly sophisticated (hearing aids). The line that separates these aids from the tools and devices used by people who are not normally considered disabled is unclear and often depends on context.

Prostheses and implants can be considered as devices that go beyond assistance to physically replace the impaired body part. At least until the recent moves towards genuine enhancement technology, the aim of using prostheses or implants was to normalise the function and form of the impaired body. Thus these devices were usually designed to behave and look as much like 'the real/normal thing' as possible, and advances focused on improving the simulation: the *value* of this generation of prostheses or implants lay in being undetectable.

Many newer forms of prosthesis and implant, however, have modified this criterion for success. The inorganic, technological features of the device are allowed to show and even become dominant, with advertising and reportage highlighting the fascination of 'bionic' arms, legs or sensory organs. In this paper I will discuss the processes, practices and problems of a shift in which the right kind of disabled body is the one that is shaped and marked by prosthetic or implant technology.

Aslihan Sanal

The third kidney: politics of organ transplants and identity in Turkey

In Turkey organ donations from cadaveric donors have been very low (sometimes around 10%). This, physicians believed, was rooted in cultural and religious taboos surrounding the dead body. Consequently, as transplants became a routine practice by the mid-1990s and poverty was widespread, living-related transplants became the core donor pool for transplant practices and organ trafficking became a natural extension of this. In time, a kidney was donated in exchange for a dowery, for an apartment, for

covering debts or less. Also for this reason, patients learned to live with another's kidney while confronting issues related with kinship, inequalities, taboos, and poverty at the same time. As such, their medical experience was deeply economic and biopolitical and so was their "second life" with the transplant.

Drawing examples from my fieldwork in Turkey, I will talk about the fragmentation of transplants' biopolitics and how this fragmentation effected patients' subjectivities in a country tainted by inequalities and poverty.

Valerie M Sheach Leith
being and becoming: the biggest loser?

Being a fat [female] body in contemporary Western society is to embody a space beyond the limits of acceptability. The fat body, particularly the fat female body, is positioned as problematic and lacking in 'value'. It is a body in need of surveillance and control, not least by self. Drawing on the work of continental philosophers and the concept of *becoming* this paper is a critical reflection on the embodied experiences of a fat woman becoming slim [mer]. Thinking through, rather than about, the body, its focus is on assemblages brought about by being a fat body and the process of cutting that fat body [self] down to size. In adopting the concept of *becoming* to analyse my engagement with the surveillance practices of the Biggest Loser (diet) Club, and the ways in which this corporeality in flux has been received by myself and others, I reflect not only on what has been gained, but also what, along with the pounds, has been lost. The overall aim of the paper is to evaluate the theoretical, political and embodied efficacy of conceptualising the body as *a becoming* for destabilising the current boundaries of the 'norm'.

Margrit Shildrick

'Why should our bodies end at the skin?': technologies, boundaries and embodiment

In the era of postmodernity, issues of bodies and technologies increasingly challenge not only the normative performance of the human subject, but also the very boundaries of what counts as human. Where in the past, the term prosthesis intended some material object that compensated for a substantive and negatively figured lack in embodiment, the emphasis now is firmly on enhancement and supplement. For many disabled people – whose interface with the world may rely to a greater or lesser extent on the deployment of prostheses – the mode of rehabilitation to normative practices is no longer the point; instead prostheses may be highly productive alternatives that inevitably queer experience itself. Going further, the notion of technological supplementarity can be transformed to encompass an understanding of embodiment as necessarily entailing assemblage -in both organic, non-organic and hybrid forms – as a mode of existence that troubles our human privilege.

Julia Twigg

Expressing, embodying and resisting: the role of clothing and dress in the constitution of the aged body

We are familiar from a range of evidence with the ways in which the body in age is stigmatised and demeaned. This applies in particular to the bodies of frail older people who are made subject to regimes of care, but it extends also to younger cohorts, as the cultural erosions of age in modern consumption culture set in early. Here ageing is seen as a form of dereliction. As Woodward argues we are not judged by how old we are, but how young we are not. Such strictures apply more strongly to women, so that with age the female body becomes both invisible, in that it is no longer seen, and hypervisible, in that it is all that is seen. In this context, clothes mediate between the

body and its social presentation. They are one of the ways in which social identities, including those of age, are made concrete and visible. The presentation will explore the ways in which older people use clothing and dress to express, embody, but also resist, the discourses of age.

Kristin Zeiler and Anna Malmqvist

An ethical analysis of lesbian biological co-motherhood: Making sense of oocyte reception and the privileging of gestational motherhood in Swedish legislation

IVF with ROPA (Reception of Oocytes from Partners) allows lesbian mothers to share biological motherhood. The gestational mother receives an egg from her partner who becomes the genetic mother. This presentation examines the ethics of ROPA with a focus on IVF-related risks for the women and the resulting child, on whether ROPA qualifies as a “legitimate” medical therapy that falls within the goals of medicine, and on the meaning and value attributed to a biologically shared bond between parents and child. We also contrast ROPA with egg donor IVF for heterosexual couples and intrafamilial live uterus transplantation (where the first world-wide case took place in Sweden, autumn 2012), and show how Swedish legislation makes certain ways of sharing biological bonds out of place. In Sweden, ROPA is illegal, egg donor IVF for heterosexual couples is allowed and practiced, and live uterus transplantation is performed within a research project. But is ROPA really ethically more problematic?

Christoph Zellweger

INCREDIBLES - negotiating the body as artefact

This paper reports on an on-going artistic enquiry into the constructed world of objects, bodies and identities. It reflects on the wide acceptance of plastic surgery and other emerging medical technologies able to aestheticize the human body and to improve its performance. The paper looks at normative aspects of body modification and critically recognises the increased use of invasive technologies as a significant cultural phenomena and expressive tool to foster social communities and increase distinction. The enquiry poses questions around how these developments may affect people’s perceptions of identity and in which way the experience of the sensible world may be altered or even extended.

The investigation builds on research undertaken in operation theatres in clinics in Switzerland since 2009. Making use of artistic strategies with an affinity to Critical Design the resulting discursive objects and installations address the cultural, social and political metamorphosis happening skin deep. The presentation will show works and their display at several exhibitions. Conclusively, the paper will suggest a possible “Corporeal Design”-practice and will point at the emerging field as the ultimate ‘embodiment’ of material culture.

Participant Biographies

Dr Edmund Coleman-Fountain

Edmund completed his PhD in Sociology at Newcastle University in 2011, and is now a research associate in PEALS. His research is on youth and identity, and he draws on qualitative interviews and visual methods to explore the stories young people tell of themselves. He is interested how the identities of young people are socially shaped, and has worked with lesbians and gay youth and disabled youth in generating accounts of what it means to be young and 'different'. He is in the final stages of the 'Embodied Selves in Transition' project, working alongside Janice McLaughlin, and is currently writing a book under contract with Palgrave Macmillan based on the findings of his PhD research.

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Dr Cathrine Degnen

Cathrine is Lecturer in Social Anthropology at Newcastle University. Trained in medical anthropology and ethnography, her research interests include the everyday experiences of ageing and selfhood, with a particular emphasis on the intersection of narrativity, social memory and place. Recent publications include *Ageing Selves and Everyday Life in the North of England: Years in the Making* (2012, Manchester University Press) and "'Knowing', absence and presence: The spatial and temporal depth of relations" in *Environment and Planning D, Society and Space* (31:4, 2013). Current research projects include 'Regarding Beauty: Transnational Understandings of Ageing Bodies, Beauty and Emotions' (with Dr Mónica Moreno Figueroa) and 'Ageing Creatively: a pilot study to explore the relation of creative arts interventions to wellbeing in later life' (MRC funded, 2011-2013, PI Eric Cross).

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Jacqueline Donachie

Jacqueline is a Scottish artist, graduating in the early 90's from The Glasgow School of Art's influential Environmental Art department, which encouraged artists to place their work in a variety of public contexts out-with the gallery space. She is still based in the city and has forged an international reputation for a socially-engaged, collaborative art practice, with a special interest in public space, healthcare and bio-medical research. Between 2001 and 2006 she collaborated with Darren Monckton, Professor of Human Genetics at the University of Glasgow on an ambitious series of works funded by the Wellcome Trust which resulted in the exhibition, film and publication *Tomorrow Belongs to Me*. She is currently working on a practice led PhD at Northumbria University.

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Professor Erica Haimes

Erica was the Founding Executive Director of the PEALS (Policy, Ethics and Life Sciences) Research Centre (1998-2008) where she is now Professorial Fellow; she is also Professor of Sociology at Newcastle University, UK. Her research interests include: interdisciplinary research on social, ethical and legal aspects of the life sciences; reproductive and genetic technologies; socio-ethical aspects of the provision of human tissue for research, and the relationship between states, families and medicine with a focus on assisted conception. She founded the PARTS (Provision and Acquisition of Reproductive Tissue for Science) International Research Network.

Erica has been a member of various policy and practice advisory bodies including: the RCOG Ethics Committee; the Ethics and Governance Council for UK Biobank; the MRC's International DNA Banking Advisory Committee; the Nuffield Council on Bioethics Working Party on the care of premature babies, and was a co-opted member of the Ethics and Law Advisory Committee of the Human Fertilisation and Embryology Authority. She is currently a member of the Ethics and Public Policy Committee of the International Society for Stem Cell Research (2009-ongoing). She is on the Advisory Board of the UK's Economic and Social Research Council (ESRC) Genomics Research and Policy Forum at Edinburgh University and on the International Advisory Board for the NIH-funded Centre for Genetics Research, Ethics and Law at Case Western Reserve University, USA.

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Professor Bill Hughes

Bill Hughes is Professor of Sociology in the *Glasgow School for Business and Society* at Glasgow Caledonian University. His research interests include disability and impairment, social theory and the body and he has taught a number of courses over a twenty five year period on a variety of sociological subjects including theory, health, welfare, the body, disability, human rights and social exclusion. He is co-author (with several colleagues at Glasgow Caledonian University) of *The Body, Culture and Society: An Introduction* (Open University Press 2000) and is co-editor – with Dan Goodley and Lennard Davis of *Disability and Social Theory* (2012). He has published in the journals *Sociology* and *Body and Society* and is a regular contributor to and a member of the Editorial Board of *Disability & Society*. He is also Editor in Chief of the *Scandinavian Journal of Disability Research*. Bill is currently working on a book with the provisional title: *Invalidation: A Social and Historical Ontology for Disability*.

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Professor Jackie Leach Scully

Jackie is Professor in Social Ethics and Bioethics at Newcastle University, and a Co-Director of PEALS. Originally trained as a biochemist she developed an interest in the social effects of science and its regulation, and in 1997 joined an interdisciplinary unit for bioethics at the University of Basel. There she was able to follow her research interests in the regulation of genetic and reproductive medicine, and in more general areas of bioethics, disability, the social construction of moral issues, and in feminist and psychoanalytic approaches to understanding moral processes. Her most recent work is on the ethics of bodies that are anomalous in different ways -- disabled, missing, fragmented -- and the role of legislation and regulation in shaping public moral imagination.

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Anna Malmquist

Anna is a doctoral student in psychology at Linköping University. Her doctoral research project focuses Swedish lesbian couples who share legal parenthood with each other. Together with Karin Zetterqvist Nelson she is responsible for the section on 'Gay and lesbian parents' in Oxford Bibliographies in Childhood Studies. Malmquist is herself a non-heterosexual parent.

Professor Janice McLaughlin

Janice is Executive Director of PEALS. Her research interests are in the areas of health and disability and her approach is influenced by ideas from within medical and social anthropology, social studies of technology and critical disability studies. Her work revolves around examining the construction of meaning and identity within various engagements; in particular those varied engagements that occur between service

users, professionals, social actors and technology. Janice's current work includes 2 ESRC projects, the first is an ethnography of paediatric genetics, exploring kinship and identity; the second is a project examining issues relating to embodiment, disability and pain from the perspective of disabled young people. Recent publications include: *Families Raising Disabled Children: Enabling Care and Social Justice*, published in 2008 by Palgrave and *Contesting Recognition* in 2011, also with Palgrave.

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Professor Margrit Shildrick

Margrit is Professor of Gender and Knowledge Production at Linköping University, and Adjunct Professor of Critical Disability Studies at York University, Toronto. Her research covers postmodern feminist and cultural theory, bioethics, critical disability studies and body theory. She has active research projects in gender and biology, the interface of disability and sexuality, and questions of subjectivity as experienced by transplant recipients and those using various forms of prostheses. Books include *Leaky Bodies and Boundaries: Feminism, (Bio)ethics and Postmodernism* (1997), *Embodying the Monster: Encounters with the Vulnerable Self* (2002) and *Dangerous Discourses of Disability, Sexuality and Subjectivity* (2009), as well as several edited collections and many articles in both humanities and science journals.

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Dr Mónica G. Moreno Figueroa

Mónica is a Lecturer in Sociology at Newcastle University, UK, in the School of Geography, Politics and Sociology. Her research, teaching and publications have developed around three main topics: the lived experience of 'race' and racism; feminist theory and the interconnections between beauty, emotions, visibility and racism; and visual methodologies, interdisciplinarity and applied research collaborations. With a Ph.D. in Sociology from Goldsmiths, University of London, Mónica has taught at Princeton University, Goldsmiths and Birkbeck College, the University of Nottingham, and El Colegio de Mexico. At Newcastle University, she is in charge of the MA Programmes in Sociology, contributes to Newcastle's MA in Latin American Interdisciplinary Studies and teaches undergraduate courses on introductory sociology, 'race' and racism and the sociology of emotions.

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Dr Aslihan Sanal

Aslihan is an anthropologist trained in science and technology studies. She received her PhD from MIT's Program in Science, Technology and Society in anthropology and history in 2005. Her first book *New Organs Within Us* (Duke 2011) is an analysis of organ transplantation practices and organ trade in Turkey where she wrote on the shifting boundaries of life and death and subjectivities. Currently she is in residence at the European Molecular Biology Laboratory, Hamburg where she began installing an oral history archive and conducting studies with scientists on the history of structural biology at EMBL.

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Dr Valerie M Sheach Leith

Valerie is sociology lecturer at Robert Gordon University, Aberdeen and also an established member of RGU's Institute for Health and Welfare research. Her research interests are in the area of the body, health care and the practice of pathology, trust, pregnancy loss, and maternal obesity. Recent publications focused on the organ retention scandal, the infant body (with Julie Brownlie, University of Stirling) and, reflecting her interest in autoethnography, a piece on the search for meaning after

pregnancy loss. Her most recent funded research is a study of relatives' experiences in relation to postmortem practice in Scotland.

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Professor Julia Twigg

Julia is Professor of Social Policy and Sociology, at the University of Kent. Her main areas of interest are the sociology of later years and old age, in particular the role of embodiment in this. She has recently completed an ESRC project on Clothing, the Body and Age which will be published in 2013 as *Fashion and Age: Dress, the Body and Later Life*, Bloomsbury. She is currently working on a related ESRC study of Dementia and Dress. In the past she has written on family carers and on bodywork in health and social care. She has particular interest in the cultural embodiment of age. She is currently co-editing, with Wendy Martin, *The Routledge Handbook of Cultural Gerontology* which will be published in 2014, and addresses the cultural constitution of age across a range of fields.

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Dr Simon Woods

Simon Woods is a Senior Lecturer at the Policy, Ethics and Life Sciences Research Centre (PEALS), University of Newcastle (UK) where he is Co-Director. Simon has a longstanding interest in the ethics of research; he is vice-chair of an NHS research ethics committee (REC) in Newcastle and is a member of the National Research Ethics Service National Ethics Advisors' Panel. Simon's early career was in the NHS in oncology nursing where he gained experience of adult stem-cell transplantation research. Simon holds bachelor and doctoral degrees in philosophy and over the past 10 years he has pursued a career of teaching and research within bioethics. His recent research concerns the ethical and social implications of early human development research, medical nano-technology and translational research for rare genetic disorders.

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Associate Professor Kristin Zeiler

Kristin is Associate Professor of Medical Ethics at Linköping University and Pro Futura Scientia Fellow at the Swedish Collegium for Advanced Studies, Uppsala University, Sweden. Her research examines how medical treatment, the use of new technology and experiences of pain and suffering can form our ways of engaging with others and the world, and our self-understandings; she also investigates intersubjective ethical meaning-making and taken-for-granted norms and values in medical practices. Her most recent works include a phenomenological analysis of parents' experiences of having a child born with intersex anatomies, a study on moral agency and relational selfhood in dementia care, and a larger research program entitled Towards an Ethics of Bodily Giving and Sharing in Medicine.

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Christoph Zellweger

Christoph (UK/Switzerland) started as a trained craftsman and maker of fine jewellery and metalwork for the high-end market. After going through a rigorous phase of questioning his role as a designer and artist-maker he developed a 'critical edge', which was manifested in his degree work at the Royal College of Art, London, where he qualified with distinction in 1993. In addition to exhibiting internationally and running his studio, he holds a professorial research post at Sheffield Hallam University since 2003. He has been a visiting professor at the University of Ulster in Belfast, at the Academy of Fine Arts in Nuremberg and at Cranbrook Academy of Art in Detroit and is

a frequent speaker to interdisciplinary audiences in Europe and America. In 2007 he published *Foreign Bodies*, a monograph, which aims to extend the definition of body adornment today.

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