

# Investigating the motivation for amputation

PROFESSOR PETER BRUGGER

The desire to have a healthy limb amputated is often dismissed as an unusual psychological impulse, but a comprehensive new study indicates it may be caused by anomalies in the architecture of the brain. **Professor Peter Brugger** shares his work

**What do you hope to achieve through your current research investigations into the disorder known as body integrity identity disorder (BIID)?**

On first consideration, the desire to have a fully-functional limb amputated must just seem a bizarre whim. By demonstrating that this desire rests on a dysfunctional neural integration of bodily information, we show that the condition deserves to be taken seriously. On top of this, the scientific investigation of the disorder allows us to gain an insight into the complex mechanisms underlying the experience of a unified body and mind. We hope that our findings will contribute to a less heated, but more differentiated debate about the ethics of elective limb amputation.

**Why are left-sided and lower extremities more frequently affected in patients with BIID?**

The left side of the body is generally more malleable than the right. This is evident in many psychosomatic and also in some neurological disorders, such as left-sided paralysis due to right hemisphere stroke, where disturbances of disownership of the affected body parts are more frequently observed than after similar incidents affecting the left hemisphere / right side of the body. One can only speculate about why legs rather than arms are predominantly affected. It is noteworthy that the areas of cortical leg representation are in close vicinity to those of the genital representations (while the representational areas of arms are close to those of the face). This may explain the erotic connotations, which in some cases accompany the desire for amputation.

**Why did you choose to employ diffusion tensor imaging (DTI) and resting state functional magnetic resonance imaging (rsfMRI) in your investigations?**

Previous work has suggested that BIID could be considered either as a syndrome of dysfunctional connections between disparate brain regions or as reflective of a disturbance in a circumscribed patch of cortex. To be able to investigate both potential mechanisms, we applied MRI surface-based morphometry to investigate local cortical thickness, but also used DTI and rsfMRI to verify whether BIID can be considered as a disconnection syndrome. DTI is a powerful method to measure structural connectivity

within the brain, focusing on white matter (ie. myelinated) fibre tracts linking different cortical or subcortical areas. Resting state fMRI analyses help to characterise the functionality of networks between different areas of interest, typically based on findings from structural analyses in the same group of subjects. A combination of these three methods would thus allow us to quantify the integrity of brain connections on both a structural and functional level as well as to investigate local circumscribed structural anomalies in cortical thickness and surface area.

**Who were your main collaborators and how did their expertise contribute to your research?**

Jürgen Hänggi's expertise is in the delineation of morphological aspects of the human brain as a function of various behavioural conditions in both illness and health. He has uncovered neuroarchitectural changes in response to intense motor and cognitive training in groups of high-achieving individuals such as golf players and ballet dancers. He has also characterised structural brain anomalies in people with genetic and developmental disorders. I have also worked with Bernd Krämer, a senior psychiatrist with longstanding and profound clinical expertise in gender identity disorder (GID). In his diagnostic work, he is confronted with both biologically- and psychosocially-caused disorders and thus guaranteed that balanced psychiatric assessment tools were used in the present project.

**Given the relatively minor attention attributed to BIID, do you have plans to increase awareness of the disorder?**

Definitely, yes. Publishing our findings is one thing, but continuing research against the background of what has been found is another. In an extension of the present project, we collaborate with an Italian research group, which aims at delineating – by functional MRI – the cortical areas involved in the integration of tactile stimuli on accepted versus non-accepted body parts. We also

joined up with an Australian team, who are focused on a variant of BIID, characterised by the desire for paraplegia. Based on case studies from Europe and Australia, we will point out commonalities and differences in the desire for limb amputation versus bilateral paralysis. Interestingly, the number of women seems to be considerably larger in those who want to achieve paralysis of both legs (abhorring the idea of amputation) compared to those whose only desire is the physical removal of the limb.



LEFT TO RIGHT: BERND KRÄMER,  
PETER BRUGGER, AND  
JÜRGEN HÄNGGI



## Mind against body

Body Integrity Identity Disorder causes sufferers to feel that their healthy limb doesn't belong to them, but diagnosis and treatment is often contentious or unhelpful. New research at **University Hospital Zurich** aims to bring clarity to this much-misunderstood condition

**MOST PEOPLE EXPERIENCE** severe distress when faced with the prospect of losing a limb. Yet in 1997, surgeons amputated the left leg of a man with a normal psychiatric examination on his demand; another patient's healthy limb was operated on before the hospital's administration barred such procedures. These patients were sufferers of what has been termed body integrity identity disorder (BIID), a rare and little-understood condition where able-bodied individuals report the strong and usually life-long desire to have a healthy limb amputated.

BIID is little-known amongst surgeons, psychiatrists and neurologists, and its prevalence, diagnostic classification and potential treatments are unknown or contentious. The anecdotal evidence of sufferers, however, suggests life-long distress and harmful or even fatal consequences from self-amputation attempts or 'backstreet' amputations. Given the serious legal and ethical questions the condition raises, more systematic investigation is clearly needed. To this end, Professor Peter Brugger, of the Department of Neurology at University Hospital Zurich, heads up a research project entitled 'Negative phantom limbs? A neurological account of the desire for healthy limb amputation', which investigates how anomalies in the brain may lie behind this condition.

The majority of individuals suffering from BIID report feeling that their unwanted limb does not belong to them, that the physical body they were born with does not correspond to their perceived 'inner reality'. This can be accompanied by erotic

feelings or a compulsion to pretend to be an amputee, but for most sufferers, the disorder manifests simply as an overwhelming desire to have the body part removed. Brugger frames this discussion by referring to the 'negative phantom limb': "The phantom limb as we know it from amputees is a positive illusion of the presence and ownership of a physically lost limb. In BIID the converse occurs: a physically present limb is not felt to belong to one's bodily self". It is this absence of the normal feel of bodily belonging that can be termed the 'negative phantom'.

Brugger also refers to the experience as 'incarnation without animation': this can be seen as the mirror image of phantom sensations in congenitally-absent limbs, or 'animation without incarnation'. According to Brugger: "Comparing these two conditions – BIID and phantoms of congenitally absent limbs – is more than playing with words: it tells us that things can go wrong on both sides of development, the physical and the representational. The commonality between the two apparently disparate phenomena is a mismatch between objective and experienced body form".

Where the condition has often been viewed as a psychological disorder, Brugger's work instead focuses on evidence of a neurological foundation to BIID. Previous data shows that most sufferers are men, and in over 80 percent of cases the legs are the affected limbs; the disorder also affects more left-sided than right-sided limbs and some patients have reported complex somatosensory disturbances such as paraesthesia and numb feelings. The condition is qualitatively similar to some rare signs after right-sided parietal lobe stroke.

These findings support the notion of a neurological origin of the desire for amputation

## INTELLIGENCE

### NEGATIVE PHANTOM LIMBS? A NEUROLOGICAL ACCOUNT OF THE DESIRE FOR HEALTHY LIMB AMPUTATION

#### OBJECTIVES

This project, supported by the Swiss National Science Foundation, attempts to shed light on a rare disorder: the desire for amputation of a fully functional limb. Widely regarded as an internet-propagated madness by some members of the medical community, it is a source of great suffering by those few concerned.

#### KEY COLLABORATORS

**Jürgen Hänggi, PhD**, Psychological Institute, University of Zurich

**Bernd Krämer, MD**, Psychiatric Outpatient Clinic, University Hospital Zurich

**Roger Lüchinger, PhD**, Institute for Biomedical Engineering, ETH and University of Zurich

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#### FUNDING

Swiss National Science Foundation

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**PETER BRUGGER** studied Biology and Psychology at the University of Zurich and obtained a PhD in Zoology in 1991. Originally an elementary school teacher, he went on to complete his postdoctoral studies in San Diego, USA and Victoria, Canada. Since returning to Switzerland, he has served as Head of the Neuropsychology Unit of the University Hospital Zurich since 2003.



**University Hospital  
Zurich**

#### INVESTIGATING THE ARCHITECTURE OF THE BRAIN

Hypothesising that the condition could be due to 'failed animation' of the limb during foetal development, Brugger and his colleagues set out to undertake a comprehensive study of individuals with BIID. Taking a sample group of 15 people with BIID for one limb, with 15 matched control individuals, the study comprised psychological, neurological and neuropsychological examinations, a series of behavioural experiments designed to investigate a possible disruption of limb ownership at various levels of sensorimotor integration and self-attribution, and MRI investigations to explore whether variations in the architecture of the brain itself could be associated with the disorder.

The results were revealing – both behavioural and neuro-architectural correlations with BIID were found. Behavioural testing revealed a faulty integration of the 'where' and 'when' of tactile stimulation: touch applied to a region below the demarcation line, or the point where the accepted body and the unwanted body part meet, is processed differently to touch applied to an area above that line. In terms of the brain structure, the researchers' analyses indicated reduced cortical thickness in a small region in the right parietal lobe, previously described as key to the experience of one's body. In addition, cortical thickness was reduced in another right-hemispheric parietal area that is known to house the primary somatosensory representation of the affected left-sided limb.

Moreover, Brugger describes a trend in his findings: "Individuals with BIID showed a distinct pattern of structural as well as functional connectivity between areas implied in the processing of different aspects of corporeal awareness, including the important attribution of ownership to own body parts". The anomalies in neurological structure exhibited by BIID sufferers may lead to diminished leg 'representation' in the brain – that is, the alterations may explain the feeling of non-belonging of the affected leg, and therefore the desire for healthy limb amputation. These results dispute the notion that BIID is a psychological quirk or a struggle for attention; instead, they point to a neurological origin for the desire for amputation.

#### TOWARDS AN EFFECTIVE CLINICAL THERAPY

Given the considerable distress for BIID sufferers, as well as the potentially devastating effects of self-amputation attempts and the complex ethical and legal questions posed by the condition, the researchers hoped in the course of their study to be able to contribute to the range of currently available therapies for BIID. "We would have especially welcomed a method that goes beyond the rather unspecific psychotherapies, which mostly help those who make a living out of them," Brugger asserts. However, possible clinical treatments have so far remained elusive. Brugger explains: "Those procedures previously successful in patients who claim a disownership of left-sided limbs after right hemisphere stroke, such as the irrigation of the left ear canal with cold water to boost those brain areas responsible for the integration of body and self, have proved to be entirely ineffective".

While treatment options remain few for the moment, the research will facilitate the development of an appropriate classification of a condition rarely considered to be more than a psychological oddity. The researchers aim to continue and extend their investigation by collaborating with several international teams, including one in Japan, a nation which currently has no reported cases of the condition. As Brugger observes: "Peculiarities in an individual's corporeal experience are given less attention in Asian societies, but any neurologically based disorder should of course manifest itself irrespective of cultural background". The Japanese research will provide a fascinating opportunity to investigate to what extent our experiences of our bodies are learned or innate: it will provide, Brugger hopes, "a springboard to research into those aspects of corporeal awareness that are shaped by both biology and culture".

Finally, in a broader sense, this research also provides a compelling insight into how neurology, and the deep structures of our brains, may lie behind the strangest of human compulsions. As Brugger puts it: "Our finding of neurological alterations in people with a longstanding amputation desire emphasises that even the most idiosyncratic behaviours, which are beyond almost everybody's intuitive grasp, can find a correspondence in the anatomy of the central nervous system".