

Submitted Sept. 2016; Accepted Oct. 31, 2016

Adding a Technological Device to my Birth Body Limb Agenesis, between Normality and Disability in France

Maxime Derian^{*,**}, Véra Savvaki^{**}, Édouard Kleinpeter^{*},
Véronique Donzeau-Gouge^{*,***}, Cristina Lindenmeyer^{**}

* Institut des Sciences de la Communication (UMS 3665. CNRS, Université Paris Sorbonne, Université Pierre et Marie Curie)

** Centre de Recherches Psychanalyse, Médecine, Société (EA 3522. Université Paris Diderot)

*** Centre d'études et de recherche en informatique et communications (EA 4629, Conservatoire National des Arts et Métiers)

Abstract

This article examines where repair ends and enhancement of the human body through technology begins, using limb agenesis as a case study. Limb agenesis is the congenital absence of one or more limbs, segments of limbs, or extremities. Our analysis focuses on the sociological and psychological issues arising from somatic vulnerability and the use of prosthetics, by studying this particular case of congenital malformation. The article sheds light on the distinction between agenesis and amputation due to physical trauma or disease, both in terms of the subject's life experience and the distinction between repair and enhancement. Discourse analysis reveals a paradox between the fragility and heroism of people with limb agenesis. It also establishes a classification system for how the prosthesis is integrated into the body, underlining its ambiguous status which lies between compensation for the disability and enhanced physical performance, between appropriation and hybridisation. We describe the methodology used in each approach, and their results are described separately. They are then cross-referenced and subjected to an interdisciplinary discussion.

Key words

Limb agenesis, Prosthetics for the human body, Human enhancement, Body schema, Body image, Prosthesis, Disability

1. Introduction

This article analyses the sociological and psychological challenges related to somatic vulnerability and technological replacement with prosthetics, using a particular type of disability as a case study: limb agenesis, i.e. the congenital absence of one or more limbs, parts of limbs or extremities, and that is not therefore the result of an amputation following trauma or illness.

There is a particular focus on the social representations of the agenetic body (with or without prosthesis), and the subjective life experience of the person with limb agenesis. Furthermore, this congenital pathology gives rise to questions about normal development of the human body and its variants. This research also provides an opportunity to examine the circumstances in which prostheses are called upon throughout the subject's life. It also touches on other aspects of being born with a physical disability that can be compensated for with technology, and refines what we know about traumatic or pathological amputees: issues with wearing a prosthesis every day, the prescription of such technical devices, the psychological consequences of missing a limb, and society's definition of what is normal and what is pathological. The decision to study limb agenesis ultimately brings us to consider the boundary between repair and enhancement: indeed, has the body of a person with limb agenesis wearing a prosthesis been “enhanced” or “repaired”?

This subject is investigated using a study launched in January 2014. The study draws on two academic fields and examines the interaction between socioanthropology and psychology, how their methodologies can be complementary, as well as their limitations and reciprocal transparency/opacity.

1.1. Limb Agensis: a brief definition and epidemiological data

There are a number of possible causes for limb agenesis: genetic (hereditary or non-hereditary), environmental (maternal illness, mother's exposure to toxic substances, drugs, or radiation), or mechanical (amniotic band syndrome) and it is very difficult, with the current extent of knowledge, to determine the specific aetiology of a given case of limb agenesis. Limb agenesis may be accompanied by other deformities, or exist alone. The number of agenetic births is hardly quantified in France¹.

¹ Although obtaining an accurate count would be difficult, in 2007 ADEPA (Association for the Rights and Research of Amputees) estimated that limb agenesis affected 10-15 children per 100,000 births in France, or around one hundred infants every year, in turn representing 1% to 2% of new amputees every year. The same organisation proposes a range of 8300 to 9000 amputees per year. 80% of them lose their limbs due to illness (diabetes, arteritis, arteriosclerosis, cancer, gangrene, etc.), and almost all of the remainder are the result of trauma. The ASSEDEA

Limb agenesis in and of itself has very rarely been the subject of research in neuroscience, clinical psychology, sociology, and anthropology [3][7]. It is more often included in studies examining amputation or developmental pathologies. It should, however, be noted that a meta study has already set out to collect and collate the various cases of phantom limbs in congenital amputees in scientific literature, in an effort to put forward a unified explanation [8].

1.2. The “Body Schema” and how it changes with technological hybridisation

This study calls upon the “body schema” concept as the theoretical foundation for understanding how a technical object is integrated into the human body. It is used both to create the socioanthropological interview guide, as well as in analysis of the results. Traditionally, this concept has three accepted meanings: the postural schema, the neural correlates of individual proprioception, and a person’s mental image of their body as a construct, in particular through social interaction. Notre étude a principalement recours aux deux dernières acceptions du terme. Our study mainly refers to the latter two definitions of the term. In psychology, the term “body image” is used to describe the mental representation of the body, and this is the terminology we will use in this article.

2. Objectives

This interdisciplinary research, drawing on anthropological, sociological, and psychological approaches, is intended firstly to advance theoretical thinking on care and prostheses design for limb agenesis in its various forms:

- The social aspects of limb agenesis, and in particular the relationship between the person with limb agenesis, their social circle, and the medical world: improvements to the general care of limb agenesis (training for healthcare practitioners, information for parents, raising awareness among prostheses manufacturers of this type of disability particular factors) as well as to the quality of life of people with limb agenesis;
- The psychological effects of limb agenesis and the use of prosthetics in adults and children, as well as in the parents of children with limb agenesis (discovery of agenesis, family dynamics,

(French association for the study and support of people with limb agenesis) estimates that limb malformations (including agenesis and dysmelia) represent around 360 births per year in France (statistical extrapolation based on the analysis of 6 regional registers covering 19% of the country).

compliance and attitudes towards healthcare and rehabilitation, limb agenesis throughout lifetime, parenthood, ageing, etc.);

- Social inclusion, identity claim of people with limb agenesis, and the role of participating in patient associations;
- Implication of final users in the construction of prosthetic devices.

From a more fundamental standpoint, our research aims to shed new light on the boundary between repair and enhancement of the human body, and the hybridisation between human bodies and technical objects. Our research also sets out to generate transferable knowledge that contributes both to interdisciplinary thinking on the human body, disability, and healthcare, as well as on the use of prostheses in these fields.

3. Methodologies

This study is based on qualitative methodology from two distinct and complementary fields: socioanthropology and psychology. The interview guidelines for each discipline were developed along the same two lines of enquiry: (i) the subject with limb agenesis when faced with the decision to use a prosthesis and (ii) the life experience of people with limb agenesis during different stages of their lives, with a special focus on the feelings of their relatives.

We interviewed both adults and children with limb agenesis, parents, healthcare professionals, and prosthetic manufacturers. Contact was generally made through ASSEDEA (French association for the study and support of people with limb agenesis), the study's associative partner².

3.1. Methodology used in socioanthropology section

The socioanthropological study was carried out in 2014 using two qualitative techniques: a semi-structured interview and participant observation. (6 meetings related to the ASSEDEA and the *European Congenital Limb Difference Network*).

The interviews were carried out in line with two themes: life experience (life story and social inclusion) and the attitudes towards different types of prostheses (aesthetic or functional). We asked the parents about their experience of having a child with limb agenesis, the therapeutic

² 28 different people were interviewed in a total of 62 interviews: 19 people for the 19 socioanthropological interviews, and 9 people for the 43 psychological interviews (with one person doing both interviews) on 15 September 2015.

choices they made, as well as any care services used. The healthcare professionals we met gave us their point of view on medical care for limb agenesis.

We used this material to outline descriptive ideal types used to understand the different ways in which prostheses were used or not used.

3.2. Methodology used in psychology section

A series of six clinical research interviews for each participant (10 per participant in the pilot phase) were used to lead participants to share and express their experience of limb agenesis, and to explore specific, intimate aspects of this experience in greater detail. The interviews were spread over a few months between 2014 and 2016, and were carried out with parents of children with limb agenesis as well as with children and adults living with the condition themselves.

The first interviews were unstructured and provided an initial free approach to limb agenesis. The next interviews were semi-structured, each beginning with a question about a particular aspect of the participant's life with limb agenesis (subjective views of limb agenesis, discovery or awareness of the condition, family and private life, attitudes towards prostheses and rehabilitation, as well as reactions in intimate situations or physical vulnerability at different stages of their lives).

With children, the protocol was adapted to focus mainly on verbal and nonverbal interactions taking place during expression activities.

4. Results

The results are presented successively for each discipline used in the study: socioanthropology and psychology.

4.1. From a socioanthropology standpoint

Although each person we met had their own specificities, the results from our various interviews highlighted:

- The difference between limb agenesis and amputation caused by trauma or illness, with regard to the reported life experience, the vocabulary used, and the justification for the choice of using or not a prosthesis;

- That a typology may be established depending on whether the agenesis affects the upper or lower limbs, and on the different kinds of prostheses used (“aesthetic”, “functional - mechanical, myoelectric, bionic”);
- The role of the family and medical environments in the general care of limb agenesis.

4.1.1. The subject’s recognition as a “person with limb agenesis”

All of the people with limb agenesis that we met said that they are “just like everyone else” and reported a good general quality of life as well as satisfaction with their social inclusion, their working and marital life, irrespective of whether they use a prosthesis or not. They made a clear distinction between their situation and that of traumatic or pathological amputees, even though society sees and considers them in a similar light.

For the people with limb agenesis we met, whether it affected their upper or lower limbs, locomotion, sports and mobility were key issues. In particular, obtaining a driving licence and the ability to use a vehicle regularly featured in our interviews.

The missing limb is often referred to using the part of the limb affected and its location, for example with the terms “right hand” or “left hand”, “right leg” or “left leg”. With children, the spontaneous vocabulary used is along the lines of “little hand”, “little arm”, “little leg”. Adults sometimes use circumlocutions: “my agenesis” to refer to the part of their body affected by agenesis, or talk about “fingerbuds”, for example. The word “stump” is almost never spontaneously used. Those asked were all reluctant to use it unless the conversation was referring to an explicitly medical context, as they believe the word to be too closely related to a traumatic amputation. Actually, the medical vocabulary regarding limb agenesis is only partially used by those with the condition and their social circles.

4.1.2. Limb agenesis, with or without prosthetics

4.1.2.1. Reasons for using or not using prosthetics

The reasons for using or not using prosthetics lead to two contrasting arguments, each bearing an internal logic.

People without prosthetics justify their decision by the fact that they can satisfy functional goals without them, by using adjusted behavioural strategies. Furthermore, not wearing a prosthesis (almost) enables them to forgo the need for rehabilitation. For some of the people we

met, the fact that they don't regularly need to see a doctor is a sign of "normality". Those who use prosthetics justify their decision and the constraints that come with it with the ability the prosthesis gives them to compensate for disability and go some way towards hiding it. It can be used to perform given functions, restore the body's symmetry and/or move towards a "normal" functional and physiological condition, to "answer questions" and "stop curious stares". Those with prosthetics also express confidence in the technical promise of an ever more satisfying replacement of the absent limb. Some even state that the prosthesis could become an integral part of themselves.

Whether they wear a prosthesis or not, all of the subjects with limb agenesis report taking ownership of their condition. Furthermore, the interviews revealed that they don't have any real demands about accommodating public spaces to their disability. However, only some of them have adapted their homes. Others adapt themselves, either by wearing prosthetics or using workaround strategies.

4.1.2.2. The different kinds of prosthetics

From the sample in our study, we have made the following observations:

- Not all people with limb agenesis choose to use prosthetics. In particular, most people with upper limb agenesis do not use prostheses, while almost all people with lower limb agenesis do;
- Among those who use prosthetics, those with lower limb agenesis use functional prostheses. Of those with upper limb agenesis, some use aesthetic prostheses, and others use myoelectric ones.

4.1.3. The role of the family and medical environment in the general care of limb agenesis

4.1.3.1. At birth

Our interviews with the parents revealed significant variations in the training that gynaecologists and obstetricians receive on i) limb agenesis and ii) their reaction upon discovery of the condition. Parents told us that they met some doctors who they felt were lost on delivering a child with limb agenesis and were unable to provide effective information and advice. Their scant knowledge of how to explain the exact causes of limb agenesis also means parents are faced

with a lack of information about the reasons behind the malformation. On the other hand, once the limb agenesis has been categorised, they say that they were faced with abundant offers of treatment for their child, offers that were not always in sync.

4.1.3.2. The decision to use prosthetics

A number of questions arise when a child with limb agenesis is born (need for reconstruction or amputation surgery, need for rehabilitation or readjustment, etc.) depending on the type of agenesis they have, and in particular whether to use prosthetics or not. The decision lies with the parents, in consultation with the doctors. It is not without consequences and determines the child's later body development, in both physical and psychological terms.

Some parents and healthcare professionals believe that early use of prosthetics gets the child used to them, making them easier to use later on. This familiarisation becomes part of a healthcare model that demands commitment and involvement from the child and their whole family. Contrary to this, the decision not to fit a prosthesis to the child lets the child experience the world with the body they were born with, and leads to the early development of compensation mechanisms, almost doing away with the need for rehabilitation.

As adult life begins, the attitude towards prosthetics seems to become set for life, even if they can change in a few occurrences (only two in our study). The study also revealed disparities in the decision to use prosthetics depending on the Rehabilitation Centre as well as the kind of limb agenesis and the specific family context of the newborn or unborn child. Today, and doubtlessly influenced by the technical potential, the parents we interviewed tend to prefer prosthetics for their child. In all cases, the parents express their need to feel reassured in their decision making.

4.2. From a psychological standpoint

The first results from our psychological interviews highlighted the effect limb agenesis has not only on the subject, but also, and first of all, on their families. When a child with limb agenesis is born it disrupts the family dynamic that will, retroactively, influence how the child grows up. All of the parents we asked said that they felt shocked when they first heard the news, and experienced feelings of incomprehension and helplessness in the face of a situation that went beyond them.

However, our interviews revealed that the parents' reactions varied depending on whether the agenesis was detected in a prenatal examination or not. If it was, the "discovery" of the limb agenesis came in two phases: one with the ultrasound, and then upon childbirth. Once the diagnosis is made, anticipation of the malformation overtakes the parents' feelings waiting for the child to be born. When the limb agenesis is not detected before the baby is born, parents regret not having had time to prepare themselves, although they admit that at least they had a less stressful pregnancy. And yet, in this case, the shock of the discovery is accompanied by suspicion of failure on the part of the medical team. Parents are in a fragile state in the period that follows the diagnosis, and are sensitive to the reactions of healthcare professionals.

4.2.1 Living with limb agenesis: the parents' point of view

The parents' stories of the birth illustrate the psychological efforts they have made since then and, the mechanisms they have developed that allowed them to invest in the child, to make room for them in the family, and minimise the traumatic psychological effects that the limb agenesis originally caused. The mothers we met, in particular, felt guilty and were worried about having to respond to their children's reactions in the future.

Among these psychological mechanisms, we observed: the recourse to medical expertise and comparison with other conditions, verbalisation, hope in technological potential, recourse to associative engagement, promoting the child's capability and strong personality.

4.2.2. Family attitudes and gender differences

Parents report that they don't treat the child with limb agenesis any different from their other children. And yet, their stories often reveal persistent concerns about the child's physical health, which may take the form of being overprotective with their body (feeding, motor development, avoiding accidents, etc.).

We noticed a few subtle gender differences in the words of people with limb agenesis and their circle. Indeed, parents generally report being more worried about girls than boys, due to the impact limb agenesis has on their physical appearance, which they deem to be more important for her than for him.

4.2.3. The person with limb agenesis and their difference

People with limb agenesis become aware that they are different in their early childhood, through reference to their material, family, and social environment, or even through certain expressions. More specifically, the awareness comes with the dissonance between the experience of body integrity, which never really existed, and the reality of a body coming to terms with its environment.

All of the people with limb agenesis that we met during the study say they accept the body they were born with. They highlight that they were “born like that” and it isn’t going to change. They also emphasise the fact that it isn’t the result of a painful accident and that they haven’t suffered through surgical amputation. And yet, they express concerns about comparisons to ideal body representations in terms of appearance and performance. They provide an answer that, while the missing limb is implicitly present, is often characterised by a quest for excellence, of “high performance”, whether in sports or at work.

People with limb agenesis, in their own words as well as those of their social circle, and healthcare professionals, demonstrate great everyday inventiveness (ability to perform daily tasks their own way, to find new ways to use different objects), despite sometimes appearing clumsy. If they fail to do something, the fact of giving up an activity is often seen to be directly linked to the agenesis or justified through an indirect link with it.

Looks and questions from other people are often mentioned and qualified to varying degrees of kindness or offensiveness, depending on the context and the subject’s state of mind. In general, people with limb agenesis don’t want to attract stares and questions, whether or not they use prosthetics, and whether or not they try to hide their agenetic limb or prosthesis. Ideally, they would want their condition to go unnoticed. And yet, although they don’t class themselves as being disabled, people with limb agenesis sometimes express their need for practical everyday support, or accept this support from others, which they justify in both cases without wanting to feel blamed, singled out, or stigmatised. When this request is made, when the limb agenesis becomes visible and is acknowledged, it is often a delicate moment greeted with certain ambivalence. The acknowledgement and respect for the passive position of the person that asks for or receives assistance seems to be an important condition for a trusting relationship with the other person, especially if it involves touching the agenetic limb.

The attention that parents give to their agenetic child’s body and its vulnerability can also be seen in the individuals with limb agenesis themselves. Anything that renders the body more

fragile (ageing, accidents, etc.) gives rise to anxiety, mainly about the loss of autonomy, and reveals that a somatic vulnerability is inherent to limb agenesis.

Gender differences are reconfigured when limb agenesis is present. Another form of vulnerability is expressed, but differently by each gender. In particular, for men, limb agenesis can have an impact on affirming their masculinity. The decision to have children may unearth fears of possibly passing the agenesis on. Adults with limb agenesis are thereby faced with concerns about its aetiology, very often the same as their parents voiced when they discovered the condition.

5. Discussion

5.1. The paradoxes expressed: between fragility and heroism

While limb agenesis is not an obstacle to family life, educational achievement, or the world of work and social inclusion, our study nevertheless reveals some complex experiences related to limb agenesis that may appear to be contradictory. We noted how the (psychologically) traumatic [1] experience of having a baby with limb agenesis for the parents contrasted with the positive image of the condition that is revealed in the discourses. It is this observed contradiction that illustrates the paradoxical aspect of limb agenesis that we will cover here by proposing crossed interpretations.

5.1.1. Fragilities. Seeking something or someone to blame

Limb agenesis shatters the parents' fantasy of the perfect child which would be, in line with their expectations, a properly formed child in good health, with ideal qualities. The question that concerns parents, and mothers most of all, is the search for something or someone that caused their child's condition and is the reason for their suffering [5]. In these cases, we always see an attempt to rationalise, to find a cause for the limb agenesis that identifies someone or something to blame.

5.1.2. Heroism. The ideal of performance

Parents often talk about how their child should be "armed" and "know how to defend themselves", a requirement that would boost the vitality, solidity, and strength [9] of both the body and character of the person with limb agenesis. The tendency for parents to highlight their

child's ability to "get on in life" suggests a lack of awareness of their sometimes ambivalent emotions associated with limb agenesis, denying part of the child's reality. People with limb agenesis are aware that they are different and publicly they talk about their condition in a positive light: "like other people" and "doing it better than other people" are phrases they often use. This tendency to perform could be interpreted as a constant attempt to answer the implicit need to "prove themselves" in an effort to regain an image of perfection they have been deprived of.

This is one of the paradoxes of limb agenesis: a source of both endurance and determination, but also vulnerability, it is not defined as an illness but rather a state of the body. Limb agenesis, despite its clear acceptance, can give rise to confusion in the subject during particular experiences in the social sphere: for example, when the agenetic limb is too obvious/noticeable when they would like it to be more discrete, or when it goes unnoticed when they would like it to be seen. In public spaces, sometimes it is too present, and other times too absent. This tension reveals an ever-present ambivalence between visibility that runs the risk of stigmatising the person, and invisibility that risks suppressing the difference. In this light, prosthetics can help to hide limb agenesis or, on the contrary, display the difference by showing off a technical object. Hiding, displaying, or forgetting the agenetic limb are attitudes that are also mentioned by subjects when discussing their prosthesis, the use of which draws the eye and embarrassing questions towards an artefact rather than the limb agenesis itself.

This tension reveals an ever-present ambivalence between visibility that runs the risk of stigmatising the person, and invisibility that risks suppressing the difference. Here we noted that in the public sphere, there is no outcry for an "agenetic culture" by the community of people with limb agenesis, like there is, for example, with some communities of people born deaf.

5.2. Body schema and technological hybridisation

The potential of technical tools which offer concrete and tangible solutions, creates the illusion that limb agenesis is not problematic, by giving the impression that it can be completely compensated for. This technical potential reduces the parental feelings of distress and powerlessness felt upon childbirth, and enables the person wearing the prosthesis to look to the future.

5.2.1. Repair or enhance. The weight of the norm

Thus, limb agenesis may be seen as a paradigmatic case for discussing the relation to what is normal, which we use as a yardstick to describe enhancement (beyond normal) [4] or repair (bringing into line with normal). It is therefore defined from the outside, by the material, social, and family environment, and reconstructed as the individual internalises it. This internalisation varies between individuals and leads those with limb agenesis to consider and perceive their own body as deficient or, on the contrary, to deem that what constitutes normal should be expanded to include the body with which they were born.

As a consequence, the use of prosthetics in the case of limb agenesis takes on an ambiguous status. It is enhancement when it adds a component to a body perceived as whole (without taking any performance boost into account), and repair when it returns a sense of completeness to a body felt to be incomplete. It is therefore the individual themselves that will define this status for their own individual circumstances. And yet, for almost all of the social and medical discourses, prosthetics are designed to repair a “deficient” body even though, from a subjective standpoint, the individual may see them as an enhancement.

5.2.2. The conditions for hybridisation

Based on our results, we define a scale for integration of the technical tool: rejection (not used at all), appropriation (tool seen as extension of body and integrated into the body schema when worn), incorporation (the tool is felt to be missing when not worn), and hybridisation (there is no subjective difference between the tool and the natural body).

The occupational therapists we met stressed the faster uptake and more effective use of myoelectric prostheses by people with limb agenesis than traumatic or pathological amputees. This integration may seem paradoxical insofar as individuals with limb agenesis using prosthetics have never had a physical and proprioceptive experience of the missing limb, and what’s more, did not make the initial decision to use a prosthesis. On the other hand, it can be explained by the fact that the person wore a prosthesis from a very young age, and in particular when learning motor control. In other words, this integration is necessarily that of a tool (in the sense of [6], and not a replacement for a pre-existing limb. For people with limb agenesis, the original status of the prosthesis is clear: it is a foreign object that does not replace anything that was there before, and whose integration will therefore take effort and time to learn.

Accordingly, limb agenesis may help to shed new light on the question of prosthetics. Presenting the prosthesis as a tool rather than a potentially “perfect” replacement for the absent

limb helps to highlight the difficulties in learning how to use the device and minimises disappointment, which is likely to encourage uptake.

5.3. Limb agenesis in the new healthcare ecosystem

Patients are increasingly independent and a central agent in their diagnosis and care planning. This is particularly significant to limb agenesis, whether for the parents (early decision to use prostheses) or the individual themselves. Limb agenesis is a lifelong condition, rather than an illness or the result of physical trauma, which is irreversible and whose effects are felt on a daily basis. This means that people with limb agenesis are de facto experts on their own condition.

While doubtlessly representing progress in a medical field sometimes deemed to be “paternalistic”, this evolution in the role allocated to the patient, this process of empowerment, also has its limits: in some cases patients risk coming up against a medical and technical system that is beyond them, and they don’t necessarily want to be responsible for the major decisions expected of them.

Conclusion

This study presents certain limitations. Firstly, it is set within the specific context of contemporary France. Furthermore, the sample is a relatively small number of people whose only congenital pathology was the absence of a limb or section thereof. None of them presented multiple congenital disorders.

This study sets out to shed light on three theoretical issues in relation to disability and the use of prosthetics: How can the concept of “normal” be redefined to accommodate the possibility of using technology to compensate for a disability? How is a technical device integrated into an individual’s body schema? How should we view the distinction between technological repair and enhancement of the human body?

Even if it can’t be directly transposed, this study sheds light on other corporal diseases that occur at birth: physical disabilities (sensory, motor, neurological), rare and/or degenerative diseases, as well as amputations occurring later in life due to trauma or pathologies. It can also shed light on cases of technological compensation of other corporal deficiencies.

This means that limb agenesis entails a unique physical experience and relationship to prosthetics. This specificity is seldom taken into account by the medical world, prosthetics

manufacturers, and, more generally, by society at large. This results in the need to deliver special training to carers, a comprehensive presentation of the different options available from specialist centres in France, better psychological care, as well as taking the morphological variations in people with limb agenesis into account for better adapted prosthetics.

Acknowledgement

The authors would like to thank the French association for the study and support of people with limb agenesis (Assedea) and all the people that acknowledged to take part in the interviews. We also thank the Ile-de-France region pour its financial support, and all members of the Lead Reference Centre for Rare Diseases for limb malformation of the Saint-Maurice hospital.

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