

BUNDESKUNSTHALLE

TOUCHDOWN

An Exhibition with and about People with Down's Syndrome

29 October 2016 to 12 March 2017

The Exhibition Team

Exhibition Manager: Henriette Pleiger

Curators:

Dr Katja de Bragança, biologist and human geneticist, founder of *Ohrenkuss ... da rein, da raus*, a magazine created by people with Down's syndrome

Dr Heinz Greuling, physicist, science journalist, and film director (ARD, WDR, 3sat, arte)

Rikola-Gunnar Lüttgenau, historian and exhibition curator, assistant director of the foundation *Gedenkstätten Buchenwald und Mittelbau-Dora*

Advisory Board:

Julia Bertmann (writer for the magazine *Ohrenkuss*, has Down's syndrome)

Prof Dr Dr Heinz Schott (former director of the Institute of the History of Medicine at Bonn University)

Anne Leichtfuß (online editor, clear language translator)

Illustrator: Vincent Burmeister

Exhibition Design: harry vetter team, Stuttgart (Alexa Brommer, Alina Lang, Harry Vetter)

The exhibition was developed in cooperation with the research project TOUCHDOWN 21: www.touchdown21.info

General Information

As the first of its kind this exhibition with and about people with Down's syndrome takes its visitors on a cultural and experimental journey through our past and present. Besides providing the first account of the history of Down's syndrome, this show also tells the story of a complex relationship. It describes how people lived, live, and want to live – people with and without Down's syndrome.

Kunst- und Ausstellungshalle
der Bundesrepublik Deutschland GmbH

Friedrich-Ebert-Allee 4
53113 Bonn
T +49 228 9171-0
F +49 228 234154
www.bundeskunsthalle.de

Geschäftsführer
Reiner Wolfs
Dr. Bernhard Spies

Vorsitzender des Kuratoriums
Ministerialdirektor Dr. Günter Winands

HRB Nr. 5096
Amtsgericht Bonn
Umsatzsteuer ID Nr. DE811386971

Konto 3 177 177 00
Deutsche Bank Bonn
BLZ 380 700 59
IBAN DE03 3807 0059 0317 7177 00
BIC DEUTDE33



People with Trisomy 21 are the best experts on Down's syndrome. (Julia Bertmann)

Developed and presented in active collaboration with people with Down's syndrome – as experts in their own right – the show comprises scientific and artistic exhibits from archaeology, contemporary history, medicine, genetics, film, and art. With its depth and lively heterogeneity, the exhibition aims at contributing to a more effective and intelligent debate on social diversity and participation, instead of providing ready answers.

The exhibition is divided into seven chapters and comprises over 100 exhibits. The language used in the texts in the exhibition, but also in the accompanying publication *TOUCHDOWN. Die Geschichte des Down-Syndroms* (TOUCHDOWN. The History of Down's Syndrome), which was developed in cooperation with the Bundeszentrale für politische Bildung, is clear and comprehensible.

Besides historical and scientific exhibits from archives, memorial sites, museums, and university research projects in Germany, Austria, and Great Britain, the show includes works by the following artists with and without Down's syndrome:

Authors of the magazine *Ohrenkuss*, Mathias Bothor (photographer), Zora Schemm, Jonas Sippel and Sebastian Urbanski (Atelier / Theatre RambaZamba in Berlin), Susanne Kümpel and Nico Randel (KUNSTHAUS KAT18 in Cologne), Markus Keuler (artist), Jeanne-Marie Mohn and Elizabeth Coleman-Link (Raw Art Foundation in Frankfurt am Main), Britt Schilling (photographer), Judith Scott (Collection de l'art brut, Lausanne), Christa Sauer and Birgit Ziegert (Atelier Goldstein in Frankfurt am Main), Samuel Cariaux, Luc Eyen, Patrick Hanocq, and Pascal Tassini (Atelier Créahm, Liège, Belgium), Rita Arimont, Richard Bawin, Marie Bodson, Erik Derkenne, Pascal Leyder (La „S“ – Grand Atelier, Vielsalm, Belgium), and many more.

Communication

People with and without Down's syndrome developed this exhibition together. People with Down's syndrome were consulted as experts on a matter with which they are well acquainted. For the first time, they are not merely the recipients of education and assistance, but take on an instructive role themselves. This communal aim required extensive preparation and training of people with and without Down's syndrome, who guide visitors through exhibition in so-called tandem tours three times a week. The pioneering educational concept of the exhibition – a cooperation between the Bundeskunsthalle and the research project TOUCHDOWN 21 – is supported by Aktion Mensch e.V.

It's a difficult word for me: participative. But I can explain what participative means: people with Down's syndrome are part of it. In the team. To make every decision themselves.
(Verena Günnel)



Tour of the Exhibition

1. Touchdown – The Landing

To begin with, there is a strange event: the arrival of a “foreign intelligence” which occupies the light, lofty halls of the Bundeskunsthalle. It looks like the strangers just landed on the roof and then moved on. There is a giant spaceship. The area is strewn with pieces of luggage and equipment, and a flag has been rammed into the floor. Their figures appear on the white walls. Foreign astronauts have landed – astronauts with Down’s syndrome. The artist Vincent Burmeister drew this scene as a life-size comic.

The aliens call themselves the “Second Mission”, because 5.000 years ago, their first settlers arrived on Earth. The Second Mission’s task is to find out how the first mission went, and what life is like for its descendants on Earth today.

The following frame story outlines the Second Mission’s expedition and serves as a report to a commission back home. This story is continued in further life-size comic scenes throughout the exhibition. The book supplementing the exhibition is the logbook of this expedition.

Down’s syndrome for others don’t know I came from the Moon or fell from the sky.
(Ruth Schilling)

2. Today –Here and Now

This room serves as a first encounter with people with Down’s syndrome and contains descriptions of individual biographies and life situations. Upon entering, visitors see an impressive series of portraits of people with Down’s syndrome by the photographer Britt Schilling. Artworks raise questions.

How do people with Down’s syndrome live in our society today, in Germany, and in other countries? Do they love, do they work, do they have their own bank account, a driving license? Are they allowed to get married and have children? Are they allowed to vote? What about their human dignity, their right to grow up?

This room enables both experiences: direct contact, but also reflection on this encounter. It is about the relationship between people with and without Down’s syndrome in our society. It is about a yearning for both normality and individuality.

3. The Invisibles – Searching for Traces the Past

In a separate room, the first thing visitors notice is a sitting ceramic figure. Then, a bit further along, a skeleton, a find from an excavation. On one of the walls, a back-lit reproduction of a historical painting with the title *Adoration of the Infant Jesus* (around 1515) illuminates the room. One of the angels looking at Jesus has that special face, that mouth, those eyes. Involuntarily, the viewer glances back at the ceramic figure. It also has the typical mouth and eyes. It is about 3.000 years



old and comes from the region which is known as Mexico today.

The skeleton next to it is over 2.500 years old. The first analysis of ancient DNA, which was recently conducted on the skeleton especially for this exhibition, was searching for evidence of Trisomy 21 (i.e. Down's syndrome) – a scientific premiere.

The figure, the skeleton, and the historical painting are among the few indications that obviously people with this genetic variation also existed in former times. But why are their traces so rare? As if they had led a hidden existence for all those centuries.

This shows that our past has almost always been told and portrayed as the story of “normal” people without “anomalies”. The search for traces is laborious and also makes us question ourselves:

To what extent are the changing categories of our perception of “otherness” responsible for creating a “Down's syndrome problem”?

4. The Great Appearance – John Langdon Down

All of a sudden, they make a historical appearance. In 1866, the English physician, Dr John Langdon Down (1828-1896), was the first to describe them and to take impressive photographs of them. Which are their defining physical characteristics?

In the middle of the room, the visitors see an old camera – similar to the one John Langdon Down might have used. It is directed towards a large canvas attached to the wall, like in an old photo studio, a chair has been placed in front of it. The canvas shows an interior view of the Victorian theatre in Normansfield near London, Langdon Down's institution for people with learning disabilities. Langdon Down photographed the residents of his two institutions Earlswood and Normansfield – to date an undiscovered treasure from English archives. This is their first big appearance. Now they have become visible, the people, their talents, their gifts, with dignity. The original patient casebooks provide insights into the biographies of people living with Down's syndrome in the 19th century.

With his concepts and methods designed to assist and enable people with Down's syndrome to lead more independent lives, John Langdon Down was ahead of his time. We are only starting to realise how pioneering his views and achievements actually were.

In this room, Langdon Down's touching and dignified photos are harshly contrasted by his colleagues' medical representations of people with Down's syndrome. These degrading portrayals of so-called “Mongolian idiots” were already common in his life time, but continued to be way into the 20th century. Explanations of the history of the terms “mongolism” and “mongoloid”, which today are perceived as derogatory and discriminating, are supplemented by an account of a trip to Mongolia undertaken by the authors of *Ohrenkuss*, a magazine created by people with Down's syndrome. In the course of his life,



John Langdon Down himself realised that the term “mongolism”, which he had helped to coin on the basis of Blumenbach’s race theory in 1866, was derogatory and misleading, and eventually stopped using it.

5. In the Twilight – The Extermination

Not long after John Langdon Down, they had to face the threat of extermination in Germany. People with Down’s syndrome could now be disposed of as “burdening existences”. At birth they were registered, categorised, and finally put into institutions. They became cases in files, were diagnosed (“mongoloid debility”), “treated”, killed.

The atmosphere in this room is oppressive – people with Down’s syndrome were made to disappear. It is hard to make out their faces, names, and stories. Doctors, nurses, and parents speak in fragmented sentences and allusions. They try to cover up their actions. And yet these deeds are irreversible. The exhibits give an idea of the insinuations and arguments that were used. A line of reasoning becomes apparent that is still common enough today.

6. Research - I am what I am

The centre of the room is occupied by a mysterious object created by the deceased artist Judith Scott who also had Down’s syndrome – a sculpture made of scraps of material and threads that seem to be concealing something (like yet to be deciphered DNA material). At some point, scientists discovered the cause of the “syndrome”: they have an extra chromosome.

What is Trisomy 21? People with 46 and with 47 chromosomes provide explanations. Visitors are given the opportunity to explore traits of the similar and of the extraordinary, also under the microscope.

“I am what they call special”, a woman with Down’s syndrome once wrote. Have we started to see people with Down’s syndrome as no more than a genetic phenomenon?

Other scientists have found out how the Down’s syndrome can be easily recognised at a prenatal stage (ultrasound, prenatal test) and diagnosed (chromosome analysis). Doctors examine their hearts, psychologists study their perception, their thoughts, and feelings, linguists analyse their writing and their special sense of language. These new insights provide new options: possibilities of support, possibilities of new, inspiring encounters between people with and without Down’s syndrome. However, this newfound knowledge also necessitates new decisions and leads to uncertainties.

New questions arise: what kind of assistance do people with Down’s syndrome need in order to lead an independent life? Which people and which familial and social structures surround and support them? How do they contribute to the diversity of our society?

In this room, the focus is once again on the present, and predominantly on familial, communal, and social issues. The terms “support” and “extermination”,



which surfaced in the course of the exhibition, have become more topical than ever. Socio-political and economic ambitions to optimise the human genome are at odds with individual wishes for integration. The artistic and scientific exhibits will trigger questions to which there can only be more than one answer.

7. The Discussion – Staying or Leaving?

At the end of the exhibition, the “Second Mission” wonders which research results the report to the “Commission at Home” should contain. After following their discussion, visitors will hopefully leave the exhibition feeling fortified and willing to engage in this social discourse.

The life-size comic figures of the “Second Mission” debate with descendants of the “First Mission”, both visually and in an audio piece. All of them are people with Down’s syndrome. Together they ponder and comment on their own history and present.

Head of Corporate Communications / Press Officer

Sven Bergmann

T +49 228 9171–204

F +49 228 9171–211

bergmann@bundeskunsthalle.de