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**Minor Interpellation by the Members of Parliament Dr. Ilja Seifert, Diana Golze
and others and the Parliamentary Group DIE LINKE (Left Party)**

– Printed Paper 17/12999 dated 4 April 2013

**Need for clarification on the work of the Contergan Foundation (Conterganstiftung)
and its Medical Commission**

Dear Mr. President,

I answer the Minor Interpellation as follows:

Question No.1:

When and by whom was the points system decided upon?

Answer:

The regulation for the granting of benefits due to Contergan defects was originally enacted by the former Federal Ministry for Youth, Family Affairs and Health on 28 September 1973 (BAnz. No. 189 dated 6 October 1973). Annex 2 of the regulation contains the Medical Points Table.

Question No.2:

What is the wording of the currently applicable points system?



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Answer:

The 14-page Medical Points Table is available as a download on the homepage of the Contergan Foundation for People with Disabilities www.conterganstiftung.de.

Question No.3:

At what times has the points system been amended, and what were the contents of the amendments?

Answer:

To the knowledge of the Federal Government there have been the following amendments to the Medical Points Table:

Annex 2 was first amended in the second amendment to the regulation for the granting of benefits due to Contergan defects dated 1 July 1977 (BAnz. No. 128 dated 14 July 1977) as follows:

“Annex 2 (Medical Points Table) is supplemented as follows:

1. In Section IV No. 1 A 1.3 the following number 1.3.1 was inserted: “1.3.1. per supernumerary dysplastic finger 0.5 points.”
2. In Section IV No. 1 B 1.2 Letter a was expanded by the following note: “for ligament instability up to stress incapacity up to 6 points.”
3. In Section IV No. 2 the following numbers 2.20 to 2.25 were inserted:

“2.20. Aplasia of uterus and/or vagina	15
2.21. Uteral or vaginal atresia	10
2.22. Uterus bipartitus or Vagina septata	5
2.23. Penile or penoscrotal hypospadias according to severity	5 to 10
2.24. Doubled kidney or doubled renal pelvis	2
2.25. Diminished body size (in comparison to the normal values of van Wistigen)	



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a) more than M – 2 Sigma	2
b) more than M – 3 Sigma	10
c) more than M – 4 Sigma	20
d) when a growth hormone deficiency is determined, additionally	10.”

4. In Section IV No. 3 – 3.9 the word “unilateral” was replaced by the words “uni- or bilateral”.

5. In Section IV No. 4 the following numbers 4.23 to 4.25 were inserted:

“4.23 Constriction of auditory canal	unilateral	1
	bilateral	2
4.24 Conspicuous dysplasia or tip of nose (flat nose) according to severity		2 to 4
4.25 Choanal atresia (blocking of the back of the nasal passage)		
	unilateral	2
	bilateral	3.”

Annex 2 was further amended with the date of 3 July 2009 (BAnz. No. 96) as follows:

“The following paragraph was inserted under Number III: Should the Medical Commission determine that a deformity in accordance with Section 6 Paragraph 1 of this regulation is present that is not listed in the Medical Points Table under Section IV, the Medical Commission is to assess the severity of the physical defect and the physical dysfunctions caused by it according to the application of Section 7 Sentence 1 and 2 as well as of Section 8 Paragraph 2 of this regulation.”

Finally, Annex 2 was further amended with the date of 12 October 2011 (BAnz. No. 154) as follows:

“In Annex 2 under Number IV.4. ‘Ear, Nose and Throat Defects’” the following number was inserted:



	Points
4.26 Absence or deformity of the equilibrium organ unilateral	5
Absence or deformity of the equilibrium organ bilateral	25

Question No.4:

Which prenatal defects arising in connection with Contergan not taken into account in the points system despite the knowledge of these forms of defect?

Question No.5:

How many persons are affected by the decision not to take certain Contergan defects into account?

To the knowledge of the Federal Government, how many of these are still living?

Question No.6:

Who took the decision not to take certain Contergan defects into account, and on what grounds (please state in detail)?

Answer:

Questions No.4 to No.6 are answered together in view of their contextual connection.

The Federal Government has no knowledge of this. According to Section 12 Paragraph 1 of the Contergan Foundation Act, those eligible for benefits are handicapped persons whose deformities “can be brought into association with the taking of products containing thalidomide from Grünenthal GmbH by the mother during pregnancy.” When these prerequisites are proven, benefits are paid. In the event that such a deformity is present that is not listed in the Medical Points Table under Section IV, the Medical Commission is to assess the severity of the physical defect and the physical dysfunctions caused by it according to the application of Section 7 Sentence 1 and 2 as well as of Section 8 Paragraph 2 of the regulation for the granting of benefits due to Contergan defects (Number III of Annex 2 of the regulation).



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Question No.7:

How many of the recognised Contergan victims currently still living have a “9” before the decimal point in the points allocated to them (e.g. 9.00 to 9.99 or 29.97)?

Answer:

235 beneficiaries have a “9” before the decimal point in the points allocated to them.

Question No.8:

Can the Federal Government exclude that in such points ratings below a threshold anything other than purely medical aspects (e.g. financial) played a role?

Answer:

The Federal Government has no knowledge that anything other than purely medical aspects have played or play a role in the allocation of points below a threshold value.

Question No.9:

Are there differences in the application of new or higher ratings between persons lying close to a points boundary and those for whom the distance is greater?
If yes, in what relationship?

Answer:

The Federal Government has no knowledge of any such differences in applications.



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Question No.10:

Who were the members of the Medical Commission from the initial appointment of the Commission up till today (please state the names and periods of activity)?

Answer:

In the first meeting of the Council of the Foundation on 6 December 1972, two Medical Commissions were established and the following members appointed:

Commission 1

Attorney Schulte-Hillen	Chairman	until 31.12.2003
Prof. Dr. Maquardt	Orthopaedics	retired (date can no longer be determined)
Prof. Dr. Feldmann	ENT	retired (date can no longer be determined)
Prof. Dr. Pape	Eye specialist	retired (date can no longer be determined)
Prof. Dr. Lenz	Internist/ Human genetics	until 25.02.1995

Commission 2

Attorney Wartensleben	Chairman	until 31.12.2003
Prof. Dr. Matthias	Orthopaedics	retired (date can no longer be determined)
Prof. Dr. Zülke	ENT	until 04.12.1975
Prof. Dr. Jünnemann	Eye specialist	retired (date can no longer be determined)
Prof. Dr. Lenz	Internist/ Human genetics	until 25.02.1995
Dr. Baumeister	ENT	from 05.12.1975 (date of retirement can no longer be determined)

In the 20th meeting of the Council of the Foundation on 05.05.1981 it was decided to merge the two Commissions into a single Commission, organised in two working groups:

Group 1

(assessed the defects of applicants who were treated in the orthopaedic clinic of the University Hospital Münster)

Attorney Wartensleben	Chairman	until 31.12.2003
Prof. Dr. Matthias	Orthopaedics	retired (retirement see above)



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Dr. Baumeister	ENT	from 05.12.1975 (retirement see above)
Prof. Dr. Jünemann	Eye specialist	retired (retirement see above)
Prof. Dr. Lenz	Internist/ Human genetics	until 25.02.1995

Group 2

(assessed the defects of other applicants)

Attorney Schulte-Hillen	Chairman	until 31.12.2003
Prof. Dr. Maquardt	Orthopaedics	retired (date can no longer be determined)
Prof. Feldmann	ENT	retired (date can no longer be determined)
Prof. Dr. Pape	Eye specialist	retired (date can no longer be determined)
Prof. Dr. Lenz	Internist/ Human genetics	until 25.02.1995
Prof. Dr. Pfeiffer	Human genetics	vom 24.11.1988 until 1999
Prof. Dr. Niethard	Orthopaedics	from 14.12.1989 (date of retirement can no longer be determined)
Dr. Graf	Orthopaedics	since 22.11.1993
Dr. Lenz	General practitioner	from 22.05.1996 (date of retirement can no longer be determined)
Prof. Dr. Koch	Human genetics	since 30.11.1999
Dr. Schulte-Hillen	Internist	since 30.11.1999

On 01.01.2004 the Medical Commission was placed on a new basis. The division into two groups was abolished.

List of members (current)

Attorney Schucht	Chairman	from 01.01.2004 until 21.01.2010
Attorney Schmitz-Rüger	Chairwoman	from 22.01.2010 until 19.08.2012
Attorney Toews	Chairman	since 20.08.2012
Prof. Dr. Koch	Human genetics	since 30.11.1999
Dr. Graf	Orthopaedics	since 22.11.1993
Dr. Schulte-Hillen	Internist	since 30.11.1999
Dr. Waldner	ENT	since 08.06.2004
Dr. Waldner	Urology	since 03.09.2009
Dr. Jünemann	ENT	since 08.06.2004
Dr. Mojto	Endocrinology	since 24.05.2005
Prof. Dr. Seitz	Neurology	since 08.06.2004
Prof. Dr. Forst	Orthopaedics	since 13.12.2011
Dr. Nüßlein	Orthopaedics	since 10.08.2011



Question No.11:

Which persons were on the Management Board of the Foundation in the period from 1972 up till today (please state the respective periods of membership of the Board and functions in each case)?

Answer:

The following persons were Management Board of the Foundation since 1972:

1972 until 1974

Chairman	Deputy	Deputy
Mr. Hemsrath	Mr. Schleifenbaum	Mr. Nötzel

1975 until 1977

Chairman	Deputy	Deputy
Mr. Hemsrath	Mr. Schleifenbaum	Mr. Nötzel
	Mr. von Unruh (from November 1975)	

1978 until 1991

Chairman	Deputy	Deputy
Mr. Hemsrath	Mr. von Unruh	Mr. Nötzel
Mr. Partzsch (from September 1978)		

1992 until 1994

Chairman	Deputy	Deputy
Mr. Partzsch	Mr. von Unruh	Mr. Nötzel
Dr. Hansen (from March 1992)		



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1995 until 1998

Chairman	Deputy	Deputy
Dr. Hansen	Mr. von Unruh	Mr. Schulz

1999 until 2000

Chairman	Deputy	Deputy
Dr. Hansen	Mr. von Unruh	Dr. Koban

2001 until 2002

Chairman	Deputy	Deputy
Dr. Hansen	Mr. Ashcroft	Dr. Koban
		Dr. Homann (from May 2002)

2003

Chairman	Deputy	Deputy
Dr. Hansen	Mr. Ashcroft	Dr. Homann
		Dr. Breuer (from April 2003)

2004

Chairman	Deputy	Deputy
Dr. Hansen	Mr. Ashcroft	Dr. Breuer

2005 until 2009

Chairman	Deputy	Deputy
Mrs. Schmidt-Zadel	Mr. Ashcroft	Dr. Breuer



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From 2010

Chairman	Deputy	Deputy
Mrs. Blumenthal	Mr. Schucht	Mr. Kreuzinger (until October 2011)
		Mr. Stempel-Herzog (since October 2011)

Question No.12:

Which governing bodies of the Foundation and Federal authorities receive the minutes of the Medical Commission?

Answer:

Minutes of the meetings of the Medical Commission were only produced up till 31 December 2003. There were a total of 24 minutes. Since 2004, in accordance with Section 16 Paragraph 6 of the Contergan Foundation Act, the decisions and assessments have been submitted to the Management Board in every individual case in the form of an expert opinion report by the Chairman or Chairmen of the Medical Commission. To the knowledge of the Federal Government, the participants in the meetings of the Medical Commission and the Management Board of the Foundation received the minutes.

Question No.13:

Since when have the Management Board of the Foundation, the Advisory Council of the Foundation as well as the Federal Government been aware of the minutes of the Medical Commission dated 22.02.1988?

Answer:

To the knowledge of the Federal Government, the minutes of the Medical Commission dated 22 February 1988 became known to the present Managing Board, the present ministerial representatives in the Council of the Foundation and the Federal Government through the public hearing on 1 February 2013.



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In its meeting on 28 January 2013, the Management Board decided to inform all persons eligible for benefits by means of a circular letter about “Carpal Tunnel Syndrome” and to draw attention to the possibility of an application for review. This was done in Circular No. 12 in March 2013.

Question No.14:

What is the position of the Federal Government today – also with a view to the study by the University of Heidelberg – regarding the above-mentioned minutes and the fact that certain Contergan defects were apparently not taken into account in the assessment of payments?

Answer:

Through the amendment to Annex 2 of the regulation for Contergan defects on 3 July 2009 it is possible for a deformity according to Section 6 of the regulation for Contergan defects that is not listed in the Medical Points Table under Section IV to be assessed according to the application of Section 7 Sentence 1 and 2 as well as of Section 8 Paragraph 2 of this regulation.

Question No.15:

Which prenatal defects have since become known that were not yet known at the time of the decision about the points system?

Which of these have subsequently been included in the system?

Answer:

Reference is made to the answer to question No.3.



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Question No.16:

Is the Federal Government – also with a view to the study by the University of Heidelberg and its recommendation for action 6.14 – prepared in future to take into account in the assessment all prenatal defects that have since become known and to make the payments associated with these retrospectively?

If yes, how will this take place in practice?

If no, why not?

Answer:

According to Section 12 Paragraph 1 of the Contergan Foundation Act, those eligible for benefits are handicapped persons whose deformities “can be brought into association with the taking of products containing thalidomide from Grünenthal GmbH by the mother during pregnancy.” When these prerequisites are proven, benefits are paid. In the event that such a deformity is present that is not listed in the Medical Points Table under Section IV, the Medical Commission is to assess the severity of the physical defect and the physical dysfunctions caused by it according to the application of Section 7 Sentence 1 and 2 as well as of Section 8 Paragraph 2 of the regulation for the granting of benefits due to Contergan defects (Number III of Annex 2 of the regulation).

[signed]

Dr. Hermann Kues

Note: This English translation is unofficial. Only the original German text carries legal authority.