

Dutch Thalidomide Symposium,
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Dr. Becker  Klinikgruppe

**Primary and secondary effects of
Thalidomide.**

**Results from the Thalidomide study of North Rhine-
Westfalia (Germany)**

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www.dbkg.de

Setting

The study targeted all Thalidomide-affected people in North Rhine-Westphalia:

n=837

202 people with Thalidomide embryopathy (24%), born or living in North Rhine-Westphalia, were recruited (female:male= 115:87).



- Thalidomide-specific questionnaire with 34 items
 - Pain DETECT-questionnaire
 - MPSS (Mainz Model of Pain Chronification)
 - SF 36 questionnaire
 - SCID-interview
 - systematic physical examination
 - X-ray, ultrasound (in selected cases)
- ⇒ Individual treatment recommendations
for physical and mental disorders for every
participant

Pattern of skeletal damages (n=202)

Twofold damage

(dysmelia of upper extremities)

89,6%

Fourfold damage

(dysmelia of upper & lower extremities)

9,9%

Concomitant damages:

Hip dysplasia

57,9%

Hip luxation

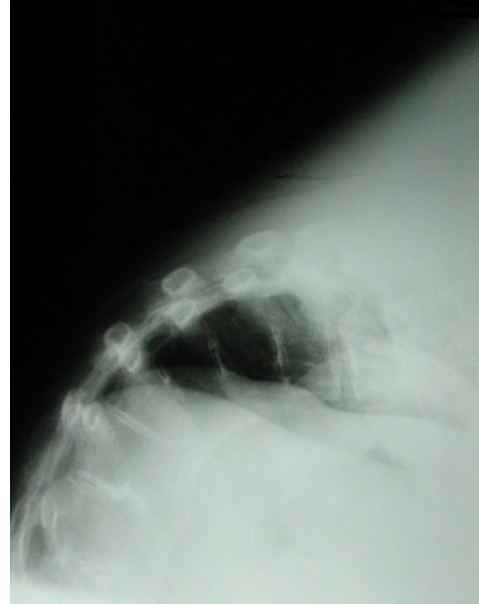
7,4%



Pattern of skeletal damages (n=202)

Spine:

Scoliosis and development disorders	68,8%
Spondylolysis/Spondylolisthesis	8,4%
Dysplasia of sacral bone	5,0%
Dysplasia of jawbone	21,8%
Microsomia (dwarfism)	9,9%



Damages of sensory organs (n=202)

■ eyes	28,2%
■ ears	
deafness	16,3%
hearing impairment	17,8%
■ flat nose	25,2%
■ cleft palate	0,5%



Internal organs (n=202)

■ heart defect	10,4%
■ intestinal malformation	7,4%
■ aplasia of gall bladder	6,4%
■ renal malformation	19,3%
■ inguinal hernia	11,9%
■ malformation of genital organs	
female (n=115)	7,0%
male (n=87)	32,5%

Consequential damages (secondary effects):

■ increased tooth wear	33,7%
■ Pain	
headaches	39,1%
neck pain	80,7%
back pain (thoracic spine)	31,7%
back pain (lumbar spine)	78,2%
Upper extremities	
shoulder	64,4%
elbow	15,8%
wrist	27,2%
hand	34,7%
Lower extremities	
hip	47,0%
knee	53,5%
ankle joint	10,4%
foot	10,9%

Consequential damages (secondary effects):

■ limitation of movement

Spine

cervical spine

36,6%

thoracic and lumbar spine

22,3%

Upper extremity

shoulder

62,4%

elbow

50%

hand

70,8%

Lower extremity

hip

26,2%

knee

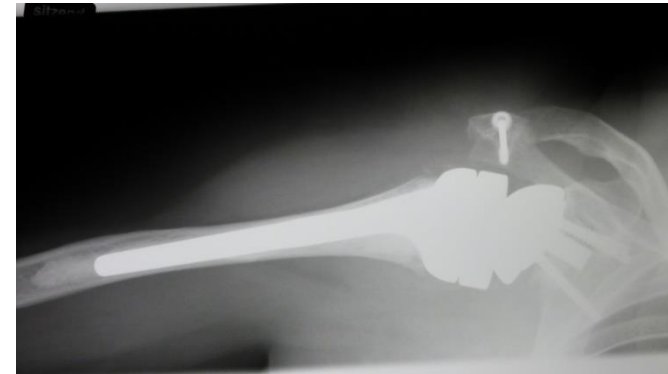
8,9%

ankle joint

7,9%

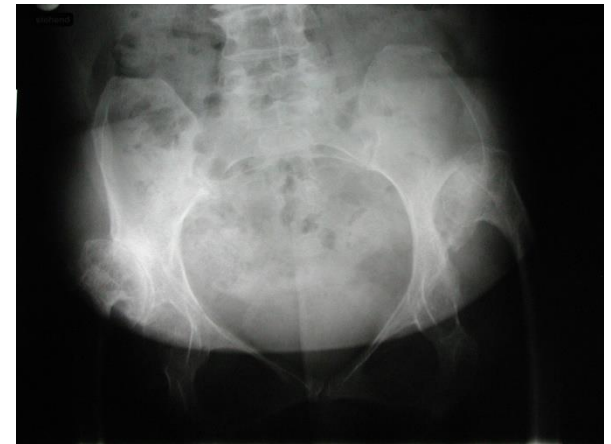
foot

4,0%



Consequential damages (secondary effects):

■ painful hypertonic muscle sections	
paracervical muscles	65,8%
trapezius muscle	76,7%
parathoracic muscles	39,6%
paralumbar muscles	35,6%
■ degenerative changes	
cervical spine	23,3%
lumbar spine	21,3%
hip	16,8%
knee	14,4%
shoulder	7,4%



Chronic pain

MPSS Stage II + III (Gerbershagen)

62,45%

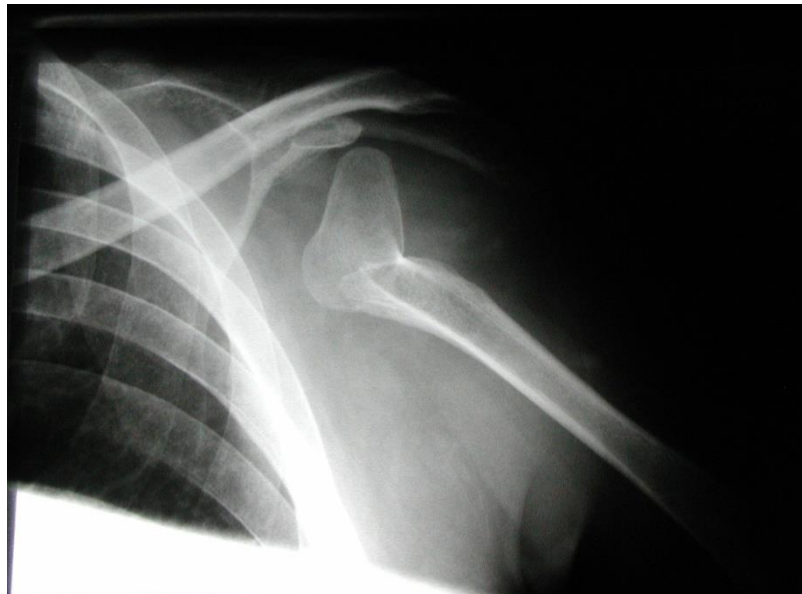
PainDETECT-Questionnaire

nociceptive pain

50%

neuropathic pain

50%



Prevalences of mental disorders

Disorder or disorder group (ICD-10 code)	4-Week prevalence (total, n=193)	4-Week prevalence (women, n=109)	4-Week prevalence (men, n=84)
Neurocognitive disorder (F0x)²	1 (0.5%)	1 (0.9%)	-
Substance-related disorder (F1x)³	16 (8.3%)	3 (2.8%)	13 (15.5%)
- Alcohol-related disorder (F10)	12 (6.2%)	2 (1.8%)	10 (11.9%)
- Medicine- and drug-related disorder	6 (3.1%)	1 (0.9%)	5 (6.0%)
Psychotic disorder (F2x)²	1 (0.5%)	1 (0.9%)	-
Affective disorders (F3x)	44 (22.8%)	25 (22.9%)	19 (22.6%)
- Unipolar depression	32 (16.5%)	18 (16.5%)	14 (16.7%)
- Dysthymic disorder	3 (1.6%)	1 (0.9%)	2 (2.4%)
- Minor depression	10 (5.2%)	6 (5.5%)	4 (4.8%)

Prevalences of mental disorders

Disorder or disorder group (ICD-10 code)	4-Week prevalence (total, n=193)	4-Week prevalence (women, n=109)	4-Week prevalence (men, n=84)
Neurotic, stress, and somatoform disorders (F4x)	52 (26.9%)	33 (30.3%)	19 (22.6%)
- Phobic disorder (F40)	24 (12.4%)	14 (12.8%)	10 (11.9%)
- Anxiety disorder (F41)	5 (2.6%)	4 (3.7%)	1 (1.2%)
- <i>Panic disorder</i>	4 (2.1%)	3 (2.8%)	1 (1.2%)
- <i>Generalised anxiety disorder</i>	1 (0.5%)	1 (0.9%)	-
- Obsessive-compulsive disorder (F42)	2 (1.0%)	1 (0.9%)	1 (1.2%)
- Post-traumatic stress disorder (F43)	6 (3.1%)	5 (4.6%)	1 (1.2%)
- Dissociative disorder (F44)	-	-	-
- Somatoform disorder (F45)	27 (14.0%)	18 (16.5%)	9 (10.7%)
- <i>Pain disorder</i>	24 (12.4%)	17 (15.6%)	7 (8.3%)
- <i>Other somatoform disorders</i>	4 (2.1%)	2 (1.8%)	2 (2.4%)

Prevalences of mental disorders

Disorder or disorder group (ICD-10 code)	4-Week prevalence (total, n=193)	4-Week prevalence (women, n=109)	4-Week prevalence (men, n=84)
Eating disorder (F50)	5 (2.6%)	5 (4.6%)	-
- Anorexia nervosa	3 (1.6%)	3 (2.8%)	-
- Other eating disorder	2 (1.0%)	2 (1.8%)	-
Personality disorder (F6x)⁴	15 (7.8%)	6 (5.5%)	9 (10.7%)
Mental retardation (F7x)²	4 (2.1%)	1 (0.9%)	3 (3.6%)
Presence of at least one mental disorder	91 (47.2%)	51 (46.8%)	40 (47.6%)
- One diagnosis ²	50 (25.9%)	29 (26.6%)	21 (25.0%)
- Two diagnoses	25 (13.0%)	14 (12.8%)	11 (13.1%)
- Three or more diagnoses	16 (8.3%)	8 (7.3%)	8 (9.5%)



Summary of physical disorders

More than 50 years after the withdrawal of Contergan painful consequential damages dominate the condition of Thalidomide survivors:

Thalidomide survivors:

62,4% pain chronicity of MPSS stages II + III

50% possible or probable neuropathic pain

Pain localisations:

neck > back

shoulder > knee > hip



Summary of mental disorders

47,2% of Thalidomide survivors with one mental disorder (four-week interval) versus 27,7% in German general population

Depressive disorders (22,8%) > somatoform (pain) disturbances (14,0%)



Consequences:

- physical quality of life ↓
- mental health ↓
- care needs ↑



Medical care system in North Rhine-Westphalia/Germany is not prepared for these problems !

⇒ consultation of doctors



hospital care



but treatment of consequential damages is not successful!



Reasons

- inadequate knowledge about the Thalidomide embryopathy and its consequences among general practitioners and medical specialists
- complex patterns of damage in Thalidomide survivors
- „orphan disease“ (837 Thalidomide survivors in NRW)
 - only a few individual patients per practice
- lack of training opportunities for general practitioners and medical specialists regarding initial and subsequent damages
- excessive distance from drug pain therapy among Thalidomide-affected people resulting in insufficient treatment



Establishment of a center of excellence for Thalidomide survivors in NRW:

Outpatient center for Contergan victims
at Dr. Becker Rhein-Sieg-Klinik, Nümbrecht

Offers diagnostic, therapeutic and advisory services in addition to
the regular medical care system in Germany



Ambulantes Zentrum für
contergangeschädigte Menschen
in der Dr. Becker Rhein-Sieg-Klinik



Range of services

- Medical diagnostics, counseling and expertise
- Therapeutic assessment, training and trial treatments
- Psychotherapeutic counseling and explanation of treatment
- Advice on aids, rehabilitation and retirement, care, assistance, individual living accommodation, applications and much more
- Concept elaboration for further treatment and initiation of „close-to-home“ care
- Treatment-accompanying prescription of necessary remedies and aid
- Follow-up visits at intervals of several months to monitor/review/check and adapt the course of therapy



Outpatient center for Contergan victims

- interdisciplinary network of various highly-qualified professional groups
- coordination of medical, therapeutic and consulting services tailored to the needs of Thalidomide victims
- development of a comprehensive treatment concept during ambulatory visit of up to four days



See you in Nuembrecht!
Bis bald in Nümbrecht!

Dr. Becker – we move lives!



further information online: www.dbkg.de/contergan

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