40 Years

Leprosy relief work from Mumbai
India

Leprosy relief work from Dinslaken
Germany

2016

“The riches we leave behind are the good deeds we did”

*Raoul Follereau*

Dr. Romana Drabik, Germany
Dr. V. V. Pai, India
In efforts towards raching
Russia and former Soviet Union countries
for a
World Without Leprosy
Part II

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Part I  - Dr. V. V. Pai

1. Introduction

Elimination of Leprosy based on the mass approach using standard Multi Drug Therapy is believed to be one of the best successful public health programmes in the endemic country in the World. In fact, the success has led to drawing parallels and lessons from the National Leprosy programme to other similar programmes of TB and AIDS in India and other leprosy endemic countries with resource poor settings. Though mass chemotherapy strategy has been able to reduce the active prevalence of the disease considerably, the challenges posed are huge due to nerve damage, disability and its consequences in the community.

2. Sustaining Leprosy Care 2011-2015 and beyond

The Enhanced Global Strategy for further reducing the disease burden due to Leprosy: 2011-2015 and beyond together with the updated Operational Guidelines seeks to enhance the following elements of the Enhanced Global Strategy:

1. Sustaining political commitment at the National and Local Government levels in all endemic countries.

2. Using the rate of new cases with grade-2 disabilities among new cases per 100 000 population as a key indicator to monitor progress.

3. Implementing innovative approaches for case-finding in order to reduce the delay in diagnosis and the occurrence of grade-2 disabilities among new cases, including examination of household contacts of cases at the time of diagnosis or within a time span close to the same and incorporating special efforts to improve control activities for populations living in difficult to access and suburban areas;
Global Leprosy Strategy 2016-2020 for Accelerating towards Leprosy free World
Strengthen government ownership, coordination and partnership

Ensuring political commitment and **adequate resources for leprosy programmes and**
contributing to universal health coverage with a **special focus on children, women and**
underserved populations including migrants and displaced people.

Promoting partnerships with state and non-state actors and promote intersectoral
 collaboration and partnerships at the international level and within countries.

Facilitating and conducting **basic and operational research in all aspects of leprosy**
and maximize the evidence base to inform policies, strategies and activities and
**strengthening surveillance and health information systems for programme**
monitoring and evaluation (including geographical information systems)

Stop leprosy and its complications

*case detection through active case-finding (e.g. campaigns) in areas of higher endemicity
and contact management.*

Ensuring prompt start and adherence to treatment, including working towards improved
treatment regimens and improving prevention and management of disabilities.

Strengthening surveillance for antimicrobial resistance including laboratory network.

Promoting innovative approaches for training, referrals and sustaining expertise in leprosy
such as eHealth and promoting interventions for the prevention of infection and disease.

3. About Bombay Leprosy Project

Bombay Leprosy Project a field based nongovernmental organization has been engaged
in leprosy relief work and leprosy research in Mumbai providing patient care services free
of costs with the help of pooled donations for the last four decades and assisting the Govt
of India and WHO in its endeavour of elimination of leprosy in India while working towards
the goal of World Without Leprosy.

Bombay Leprosy Project in the course of its field based research work which is undertaken
by its dedicated medical and paramedical team has carried out pioneering activities in the
field of leprosy since its inception in 1976. Some of the important and notable contributions
have been in urban leprosy control strategies, rationalisation of treatment and study and
practice of newer drugs, reaction management, Deformity care and prevention of
deformities, continuing medical education and integrated rehabilitation. In fact some of the
strategies in urban leprosy control, rationalisation of treatment and management of
disabilities have become a part of the policy of the National Leprosy Eradication
Programme in India and also beneficial in other endemic countries.

4. Collaboration between International Institutions and Russia

Dr. Romana Drabik an eminent Physician and Leprologist from Germany has been
instrumental through her gigantic efforts in bringing together the expertise and experience
from various institutions like WHO, Sasakawa Memorial Health Foundation, Bombay
Leprosy Project and other organizations to be made available and for capacity building of
the Resource persons from Russia and other former Soviet Union countries.

5. Bombay Leprosy Project reaches out to countries of former Soviet
Union

The first association **was in 1986 when** Dr. Ganapati visited Würzburg, Germany for
participation in Symposium on Multidrug Therapy in Leprosy. GLRA organised this
symposium in cooperation with the institute of Experimental Biology and Medicine, Borstel
and the University of Wurzburg. Many eminent Leprologists accepted the invitation and
participated in the meeting. It was for the first time in the history of the fight against leprosy
that the rigorous implementation of a treatment programme had succeeded in efforts
towards eradication of the disease from a whole area of Malta as per Prof Dr. E Freerksen
an eminent scientist.
1990
Dr. Romana Drabik for the first time visited Bombay Leprosy Project for discussions with Dr. Ganapati in Mumbai.

Subsequently at a meeting in USA, Dr. Ganapati shared with all the participants his new booklet on Modulan during the 14th International Leprosy Congress, Orlando, Florida, USA held in 1993.

Later during the 2008 17th International Leprosy Congress held in Hyderabad, a meeting with Dr. Ganapati and Dr. Pai renewed the contacts while refreshing the old friendship and it was decided to strengthen the fight against leprosy together in pursuit of the goal of ‘World Without Leprosy’. It was then decided to provide specialised training in leprosy at Bombay Leprosy Project for Doctors from the countries in former SU.

It is also important to point out here that in 2008 Bombay Leprosy Project (BLP) had an unique opportunity of projecting its academic activities to scientists from three countries where leprosy is not a problem. Dr. R Ganapati, Director Emeritus Bombay Leprosy Project was then invited to deliver guest lectures on leprosy in Japan, France and Russia.

Dr. R. Ganapati, delivered guest lecture to an audience of dermatologists and leprologists in these countries:

2008
Federal Leprosy Research Institute of Astrakhan, Russia International Conference of Dermatologists and Leprologists of Russia on 16-17, October 2008 in commemoration of its 60th Anniversary: It is unusual for a country like Russia where leprosy is well under control, to honour a Leprologist from India. Dr. Ganapati dealt with care and rehabilitation of the leprosy-disabled in his two lectures, Advice regarding management of difficult cases was sought at a special session held at the Research Institute’s clinic and hospital.

Dr. V. V. Pai, BLP was also invited to these countries to participate in the meetings and he gave a talk on Leprosy the Leprologists, Dermatologists and Research scientists assembled in the Conference at Astrakhan.

Dr. R Ganapati and Dr. V. V. Pai participated in the International Conference on Leprosy at Astrakhan Russia. Dr. Ganapati and Dr. Pai presented papers on POD and Rehabilitation in Leprosy from 16th Oct to 17th Oct 2008.

Dr. Azizullo Kosomov Director Leprosy Institute Tajikistan deputed to study Leprosy Programme POD activities and rehabilitation programme from 11-3-2008 for one week.

2009
Dr. V. V. Pai invited to participate in the International Scientific Conference at Kysl Orda Kazakhstan. Dr. Pai gave a presentation on Leprosy In India in the conference from 15-10-2009 to 16-10-2009.

2011
Dr. Romana Drabik visited BLP in 2011 for understanding the urban leprosy challenges and the possible strategies implemented by BLP to address these issues.

Dr. Romana Drabik examining leprosy patients and discussing with Dr. Pai at the Referral Centre of Bombay Leprosy Project

2012
Dr. V. V. Pai participated and presented paper on “Situation of Leprosy in India – Experience with reference to Diagnosis, Therapy and Rehabilitation at Bombay Leprosy Project” at the 4th World Congress of Tele Dermatology, at Tbilisi, Georgia from 3-10-2012 to 8-10-2012.

2013
Dr. George Edward, Dermatologist from Georgia visited BLP for training in Leprosy from 1-11-2013 to 31-11-2013.

Dr. Romana Drabik convened a meeting of the Leprologists from Russia and from the countries of former Soviet Union and Dr. V. V. Pai Director BLP for review of the work and plan for the future training during the 18th International Leprosy Congress, held in Brussels, Belgium in December 2013. The group later visited Dinslaken in Germany for a review meeting and also participated in the Lepra March conducted for creating awareness on Leprosy amongst the people in Germany and for fund raising to support the leprosy eradication programme. The group was well received by the Hon Mayor of Dinslaken who
hosted a reception on behalf of the city of Dinslaken and assured full support to the programme. All the members of the group presented to the Mayor in brief the status of the leprosy programme and highlighted the challenges in the eradication drive.

2014
As per the directions of the Health Ministry of Govt of Tajikistan, an International Leprosy Expedition was undertaken for two weeks by a team of Experts comprising Dr. Romana Drabik, Dr. V. V. Pai, Dr. Azizullo Kosomov, Dr. Tsemba V and Dr. Moldagali to study the scenario of leprosy prevalence and disease burden particularly in the difficult and remote and tough areas bordering Tajikistan and Afghanistan despite daily danger to life. Keeping with the slogan of the team “We are strong” the team successfully carried out the visit and submitted its report to the Ministry of Health, Govt of Tajikistan.

2015
Dr. Romana Drabik visited BLP from 20th January to 4rd Feb 2015.
Dr. Victor Duiko and Dr. Tsemba Viacheslav Leprosy Research Institute Astrakhan Russia visited BLP for training from 20th Jan 2015 to 4th Feb 2015.

2016
Dr. H Zamira and Dr. Yuldasheva Manzura from Karakalpak Leprosarium Uzbekistan Karakalpakstan visted BLP for Training in Leprosy from 1.3. 2016 to 12.3. 2016
Dr. Romana Drabik visited BLP from 1.3. 2016 to 14. 3. 2016 for discussions on urban leprosy specially issues related to stigma and discrimination and the presentations for the ILC China to be held in September 2016.

6. Conclusion

Despite leprosy being declared eliminated, the disease burden comprising clinical problems and nerve damage and its consequences including new 14 cases in the community pose a tremendous challenges from the management point of view.

Through the Comprehensive Leprosy Care and Management approach, BLP has attempted to identify the possible magnitude and the type of clinical problems seen at the Referral Centre and in the field and identify the strategies and efforts required to provide quality care and services to improve the quality of life of leprosy patients. We believe that concerted and consistent efforts supported with adequate resources will go a long way in the efforts towards reducing the disease burden in the community to accelerate towards a leprosy free world.
Delegates at the International Conference in Astrakhan

Dr. Pai and Dr. Azizullo at Leprosy centre in Dushanbe

Dr. Drabik and Dr. Pai examining patients at Astrakhan

Dr. Drabik engrossed at BLP Referral centre
Dr. Romana examining patients at BLP Referral centre

Dr. Manjura on completion of training at BLP with Dr. Drabik and Dr. Pai

Dr. Zamura on completion of training at BLP with Dr. Romana and Dr. Pai

Dr. Pai and Dr. George Arveladze from Tbilisi visited rural POD programme in Thane near Mumbai

Dr. Pai and Dr. George Arveladze from Tbilisi visited rural POD programme in Thane near Mumbai
7. Acknowledgement

We are thankful and indebted to all the Donors, Well wishers, Govt, Research Collaborators, Staff and the patients for their cooperation and support to Bombay Leprosy Project.

Part II - Dr. R. Drabik

Foreword T. Groß, Deputy Mayor of Dinslaken

The town of Dinslaken sincerely congratulates Leprosy Relief Work Dinslaken on its 40th jubilee. These congratulations include my thanks for the work that has been done so far as well as the respect of the invaluable work for people in need all over the world.

Over the last 4 decades, people suffering from Leprosy and Tuberculosis have been supported by the town of Dinslaken in different ways. In addition to the personal commitment of Dr. Romana Drabik, many individuals and organisations from Dinslaken and the immediate vicinity have contributed by donating general material and organizing generous financial support. Therefore, I would like to express my sincere thanks on behalf of the town of Dinslaken to all those who have been committed to the relief of leprosy and tuberculosis over the past years.

This relief work is organised by Dinslaken, a town of 68,000 inhabitants on the edge of the Ruhr Area in North Rhine Westphalia, which offers a good infrastructure and living conditions. Our citizens support people in need and thus help Dr. Drabik and the Leprosy Relief Work Dinslaken to decrease leprosy in the world. Leprosy is curable and the town of Dinslaken would like to contribute to fighting this disease.

I have been following this work with great interest for many years and I am always fascinated by the many ideas for relief projects, the unlimited personal dedication and the international network of experts, health experts and politicians. The care and support of people in need is therefore not only a regional task of a town or country but only leads to success as a collaborative concern for the people in the world. Where help is necessary for curing leprosy, the help and support of all people is necessary. Solidarity is distinguished by the support of all and the fact that people are not abandoned to their fate.

I therefore wish Leprosy Relief Work Dinslaken further success with their various projects.

Many thanks to the numerous supporters and helpers for their commitment accompanied by the wish for success in the future.

May God’s Blessings be with you in your work.

Thomas Groß
-Deputy Mayor of Dinslaken-
Town of Dinslaken
1. My first meeting with the leprosy outcast in Africa 1976

In February 1976, I went on my first trip to Kenya. There I discovered a group of young, mutilated men in the streets of Mombasa. They were sitting on wooden boards, which were fixed to roles. They painfully moved on these rolling boards by means of their mutilated hands and arms. Their faces were cruelly distorted. They were begging. Nobody paid attention to them. Obviously they were outcast. Tourists were walking around these horrible figures keeping their distance. They turned away from them in disgust. Very rarely did they throw a few coins towards them.

I have never forgotten this horrible picture, which always stayed in my mind. I did not dare take photos of them. This would have been undignified behaviour.

I realized that mere consternation and horror would not change this situation. At the same time I knew: I had to act and start doing so myself!
2. Looking for more leprosy outcast in Africa between 1976 – 1979

I could not forget the streets of Mombasa with their outcast, mutilated people. I thought about that – why? Thousands of tourists travelled to Mombasa every year. Thousands of tourists saw those mutilated faces, those horrible figures. They walked around without taking any notice of them, as if they had not seen anything.

However, I went back to Africa every year, to the West of this continent: to Gambia, Senegal, Benin, Togo. Everywhere I looked for those unhappy people and I found them everywhere. They were despised, outcast and treated like garbage. But to me each single person was important. They were humans; humans like my family and me. I studied the diagnosis and therapy of leprosy in a hospital in Lome, Togo. Then I thought: Now is the time to start organizing Leprosy Relief Work.

3. Starting to fight leprosy in India

I was very surprised about the WHO Statistics. The highest number of leprosy patients was not in Africa but in South East Asia, with India at the top covering 4 million patients, 36% of them suffering from the multibacillary form. I immediately decided to start my work in India, as it is the doctor’s main task to interrupt the chain of infection.

1980 – 1985 A village was built in Wadakanchery near Trichur

We managed to build a village for leprosy patients who were living on the streets of Kerala, disabled and mutilated and entirely on their own on an area of 5 kilometres. I am very happy that they found a new home in this village. There were about 100 people including family members who had asked for admittance and promised to care for the patients. Nurses delegated by the Bishop carried out the medical care. There were 40 tiny houses with small gardens, a little hospital, a small house for four nurses, some wells to secure the water supply and a community room, which was mainly used as a work shop. There, the patients and their families produced candles, baskets and other items. Selling these objects lead to “Help people to help themselves”.

Illustration 4 – Survey in Togo

Illustration 5 – we built a new settlement for our patients
1985 – 1987 Case finding in North India

In 1982, WHO announced: “Leprosy has become a curable disease”. Therefore, this was the starting point of the project to find also people showing the first symptoms of the disease. Well-trained nurses for case finding in leprosy went from house to house in Uttar Pradesh, Punjab and Kashmir Jammu in order to detect new cases. After two years this project was stopped due to political troubles.

Result: 360 leprosy people and 140 tuberculosis people were detected. Bishop Hippolytus from Srinagar, Kashmir, paid us a visit in Dinslaken in 1987 in order to explain the difficult situation to us. The remaining amount of money was used to build a Meeting House, which was also open for leprosy patients of the entire region.

1988 – 1993 Case-finding in South Madras

Upon request of the Indian Government, the German Leprosy Relief Association (DAHW) launched a leprosy control programme in 1981 for the North of Madras. The Government wanted to take care of their own programme to fight leprosy in the South of Madras. This did not go beyond a Letter of Intent. During the 13th International Leprosy Congress in the Netherlands in 1988, the DAHW, Würzburg, and Leprosy Relief Work Dinslaken agreed to take care of a separate leprosy project for South Madras. Dr. Lobo, our contact person, was in charge of the realisation of the project in South Madras. The aim was to eliminate leprosy in South Madras in an area of 18 square kilometres with a population of 330,000
inhabitants. The result: 2,581 leprosy people were detected within this period, and 2,365 of them were cured.

Illustration 9 – Check-ups in Slums

In 6 months, a leprosy out-clinic “Bernard Clinic” was ready, financed by Leprosy Work in Dinslaken. Then, we built houses along the street for cured but outcast patients. Its name is “Dinslaken Street”. We have managed to support the Rehabilitation Centre of this health centre intensively.

I will never forget my last conversation (2008) with Pater Dr. Luigi Pezzoni in Nalgonda. He said, “Romana, I have succeeded in building a paradise on Earth for leprosy patients.”

Illustration 10 – Leprosy March in Madras to gain the public’s interest in Leprosy

Illustration 11 – dressing-room in the In-clinic in Nalgonda

Illustration 12 – Leprosy Health Centre, boarding school

4. Our new project in 16 countries of former Soviet Union 1990 – 2016 and beyond
The idea to look for leprosy people there came up in January 1990 during a flight to India. For me, this was a historic flight, which took me right above the Soviet Union for hours. I asked myself, “Are there also any leprosy people in this enormous country?” This question came back to me repeatedly.

I decided to check this information at the WHO immediately after my return to Dinslaken. However, something surprising happened. I heard some people speak Russian in the streets of Madras. They were scientists from Riga. I learned from them that there was a leprosy centre in Latvia, not far from the capital. This information was sufficient for me to check if this was true. And it was true.

At the same time, something unexpected and shocking took place: the great power Soviet Union collapsed. Thus, the way into this new country was open for us. Together with my husband, I started a series of exploring trips.

The new region covered 1/6 of the inhibited Earth’s surface. The area of the former great power now consisted of 16 independent countries:

- **The Baltics**: Lithuania, Latvia, Estonia.
- **Eastern Europe**: Ukraine, Belarus, Moldavia
- **Caucasus**: Armenia, Georgia, Azerbaijan, a small part of Russia
- **Further to the East**: Russia
- **Around the Aral Sea**: Kazakhstan, Uzbekistan, Karakalpakstan, Turkmenistan
- **In the South**: Tajikistan and Kyrgyzstan

**Leprosy Centres in these big regions:**

The Baltics:
- Lithuania – Leprosarium Memel-Kleipeda
- Latvia – Leprosarium Talsi
- Estonia – Leprosarium Kuuda

In Eastern Europe:
- Ukraine – near the border to Moldavia - Leprosarium Kutschurgan
- Belarus – only some cases of leprosy in foreign leprosy centres

Caucasus:
- Azerbaijan – Leprosarium Umbaki
- Georgia – leprosy patients in foreign leprosy centres
- Armenia – only some cases of leprosy in the country and in foreign leprosy centres

Aral Sea:
- Kazakhstan – Kasleprosarium and some leprosy out-clinics
- Uzbekistan – Leprosarium Bachmal
- Karakalpakstan – Leprosarium Krantau
- Turkmenistan – Leprosarium Hodscha

South East Asia:
- Tajikistan – Leprosarium Hanaka
- Kirghizia – Leprosy in-patients were transferred to Kasleprosarium, out-clinic patients in the country

Western Central Asia:
- Russian Leprosy Research Institute
- Russia – Hansen Out Clinic and In Clinic Astrakhan
- Russia – Hansen Clinic Zielona Dubrawa
- Russia – Hansen Clinic Abinski
- Russia – Hansen Clinic Terski

From all these leprosaria, only the following still exist nowadays:

1. Leprosarium Umbaki in Azerbaijan
2. Hansen Clinic Astrakhan in Russia
3. Hansen Clinic Abinski in Russia
4. Hansen Clinic Terski in Russia
5. Hansen Clinic Zielona Dubrawa in Russia
6. Kasleprosarium in Kazakhstan
7. The Leprosarium of Krantau was transferred to Nukus
8. Hansen Clinic Hanaka in Tajikistan
Leprosy situation in all these countries:

Lithuania
During the last years of the 19th century, leprosy cases were detected in the region of Memel. Professor Robert Koch was commissioned to state the extent of the disease and to recommend how to fight it. In 1897, a Leprosy Congress was held in Berlin leading to the decision to isolate all leprosy cases in a “Leprosy Home” under the supervision of a medical doctor. This leprosy home was inaugurated in August 1899. The number of leprosy patients increased continuously and probably reached a number of about 30 persons.

This Leprosy Home was closed within a few hours in 1944 at the end of World War II and the patients were transferred partly to the Leprosarium Talsi in Latvia or the Leprosarium Kuuda in Estonia. Others could not be traced later on. Due to the War, there were no lists regarding the distribution of patients. Since the period of incubation is extremely long, there might be single leprosy cases in Lithuania that might be treated under different diagnosis.

In order to give these patients the possibility of being diagnosed correctly, I gave a lecture at the University of Memel/Klaipeda in April 2013 to remind the dermatologists of the symptoms of leprosy.

Illustration 13 – A lecture - diagnosis and therapy of leprosy at the University in Klaipeda, 2013

Latvia
In 1992, I visited the Leprosarium Talsi in Latvia together with my family. The medical doctor in charge, Dr. Janis Smits, informed us that he had 25 leprosy patients in the leprosarium at that time. The number of new cases had increased over the previous years.

Just before our arrival, there was a new patient, a woman of about 30 years, suffering from multibacillary (MB) form with facies leonina. Dr. Smits told us that he had sufficient specific medicine for his patients.

The centre of the Leprosarium Talsi was a Baptist church that – according to Dr. Smits – had been transformed into a leprosy museum in 1945 in order not to be destroyed. In the sanctuary there was a painting made in 1938 by the Latvian artist and writer Zanis Sunins, showing Christ among leprosy patients. In the front part of the church there were two big vitrines containing Moulages – wax models of body parts deformed by leprosy. Among the exhibits we saw maps containing statistics about the extension of leprosy in Latvia.

In 2006, the Leprosarium was closed for economic reasons. All patients have found new accommodation. Even Dr. Smits does not have any contact with them. He does not know where they are.

Illustration 14 - Path breaking to the Leprosarium
Estonia

Our first stop during the trip to Baltic countries was in Estonia. We were travelling by minibus, loaded with specific and general medicine as well as medical items and clothes. The aim of this trip was to find out about the situation of leprosy patients in all Baltic countries and to obtain statistics and get into touch with medical doctors there. Dr. Anne Sarv accompanied us to the Leprosarium Kuuda, which was over 100 years old. At this time there were in Estonia 23 patients altogether. Six of them were in Leprosarium Kuuda. We could check them. Some patients we visited in their flats in Tallinn, the capital of Estonia. I am still in touch with Dr. Sarv. She visited me in Dinslaken several times and also Würzburg, the centre of the German Leprosy and Tuberculosis Relief Association, DAHW.

The Leprosarium Kuuda was closed in 2005 for economic reasons. Now there are eight patients in Estonia (2016)
Eastern Europe
Ukraine

Illustration 20 - Leprosarium Kutschurgan

Illustration 21 – check up of a new case

Thanks to the Lecturer of the University Odessa in Ukraine, who took part in the International Congress of Polonia Medica (1995) and whom I met during the coffee break, I learned about the Leprosarium Kutschurgan in her country. Establishing first contacts with the Health Ministry and the Leprosarium was very difficult. Only in 1997 did I succeed in visiting this country and getting in touch with the Leprosarium. I was not allowed to hand over the medicine MDT that we had brought with us to Dr. Waldemar Naumov, Director of the Leprosarium as they were still at the Customs. However we were very welcome by the medical doctors and patients in a very friendly way. They stayed in small houses and were well looked after. At that time there were 45 patients, all of them suffering from impaired vision, four of them were blind. All of them were suffering from ulcers on the legs and were disabled.

In order to keep in touch with the Ukrainian patients, we invited Dr. Juri Rybak, who was very cooperative and also spoke English. In the meantime, he has been to Germany, to Dinslaken and also the DAHW in Würzburg.

My 2nd visit took place in 2004. The reason for this visit was a new patient, suffering from multi-bacillary form. He had come all the long way from Eastern Ukraine and knocked on the door of the Leprosarium Kutschurgan, telling the head physician, “I am your new patient”. Presumably, Eastern Ukraine is an endemic region. This, however, has not been verified. At that time there were only 39 patients. 35 of them completely disabled.

In 2009, Dr. Rybak took part in the International Leprosy Congress in Hydarabad, India.

In 2012, the WHO ambassador Mr. Yohey Sasakawa visited the Leprosarium Kutschurgan with his team in order to see the medical and social situation of the patients. It was an interesting and informative trip for all of us.

The patients of Leprosarium Kutschurgan are cured, and the number is permanently decreasing. In the year 2016, only 8 patients are left.

Dr. Juri Rybak is the successor of Dr. Naumov, who has retired.

Illustration 22 - Dr. W. Naumov, the new patient, Dr. J. Rybak (from left to right)
Moldavia
The Ukrainian Leprosarium Kutschurgan is located near the border to Moldavia. Therefore, all Moldavian patients were transferred to Leprosarium Kutschurgan and stayed there for the rest of their lives.

Belarus
Upon my request at the Health Ministry in Minsk in 2010, I received the following information: “No leprosy cases have been registered within the last four decades.” During my travels through the republics of the former Soviet Union, I found one patient in one of the Russian Hansen Clinics. She is cured and well looked after. Belarus, however, is known to me for the relatively high infection of tuberculosis.

Caucasus
Armenia
In the year 2000 I visited the Caucasian countries of Armenia, Georgia and Azerbaijan for the first time. The most important dermatologist was Professor Karen Babayan, whom I had known since 1999 when we met at the Central Asian Leprosy Conference in Almaty. He organised a meeting with dermatologists at the Institute of Dermatology in Erevan, the capital of Armenia. Dr. Oganesian Samwel, the country’s leprologist informed me about the 14 out-patients of the country as well as 20 in-patients who were treated in leprosaria in other countries. Together we visited the patients who lived in Erevan. I started a MDT therapy for one patient suffering from a multibacillary form. The contact with Armenia is still continuously good. Dr. Organesian repeatedly took part in training conferences in Astrakhan. Professor Babayan presented the situation of leprosy in Armenia during the International Leprosy Congress in Hyderabad, India. According to Professor Babayan, Armenia is now free of leprosy following a successful MDT therapy of 17 out-patients. Control check-ups of the contact persons, however, are still necessary.

Georgia
I covered the distance between both countries by crossing the high Caucasus mountains by taxi. This was my first contact with Georgia. Despite the agreement, no medical doctor took part in the Central Asian Conference of Leprosy in Almaty Kazakhstan, in 1999. The trip to Tiflis did not seem complicated with regard to a specific plan. The Director of the Dermatological Institute, Dr. Lali, promised to organise a training for dermatologists in...
leprosy. However, this failed, as Dr. Lali emigrated with her family within the following months. The next attempt to organise a meeting with Georgian medical doctors failed as well. In the year 2010, a World Congress of Polonia Medica took place in Thorn. The Georgian medical doctors attending this Congress invited me to a regional conference in Lagodechi, Georgia. This was an occasion for me to get into contact with the University again. Professor Tina Kituashvili was very interested in the problems concerning leprosy in her country. My suggestion was to check-up the contact persons of Georgian leprosy patients who were in leprosaria abroad. Since I already had lists containing the names and data of these patients, I could discuss this matter with Professor Kituashvili and Mr. Shota Tsanova, Vice Director of the National Centre of Disease Control. However, Mr. Shota promised to consider this.

I returned to Georgia several times. In 2012 I went back to Tbilisi to present the leprosy situation of the country at the Georgian World Congress of Teledermatology. There I met my friends Dr. Vyacheslav Tsemba the, Representative of the Director of the Russian Leprosy Research Institute in Astrakhan, and Dr. V. Pai, Director of Bombay Leprosy Project, India. We all were extremely happy to be able to meet the well-known leprologist from Brazil, Dr. Jaison A. Barreto, MD, PH.D, Chief oft he Leprosy Section Instituto Lauro de Souza Lima Baurau-SP.

The topic of check-ups of leprosy patients’ contact persons was also discussed in this group again.

Meanwhile, two young dermatologists have attended a training programme in leprosy, one of them; Dr. George Arveladze in Bombay Leprosy Project with Dr. Pai in November 2013 for one month. The second physician from Georgia Mrs Dr. Sophico Liluashvili followed a training in Leprosy in Brazil, with Dr. Jaison A. Baretto, from November 9 to December 12, 2012, also for one month.

An excellent cooperation developed with Professor Tina Kituashvili of the University in Tbilisi. So she took part actively in a group of leprologists on the occasion of the Dermatological Congress in Astana, Kazakhstan in 2012 and the International Leprosy Congress in Brussels, 2013, together with 12 doctors from countries former SU.

In the autumn of 2015, I was again invited to hold a lecture at the University of Tbilisi on the occasion of the International Jubilee Congress in Tbilisi. The topic was “An old disease with a new look”. Contact with Georgia is not only stable but extremely friendly.
Azerbaijan

In 1998, I visited Azerbaijan for the first time, following some correspondence with the Ministry of Health in Baku. I also transported by plane big cardboards of medicine – MDT, which I had received from German Leprosy and TB Relief Association (DAHW) in Würzburg. Mr. Ibraimov, representative of the Ministry of Health in Baku, met us at the airport and was able to collect all the donations we had brought with us. At the time, there were 95 leprosy patients in Azerbaijan, some of them were out-patients and the others were in Leprosarium Umbaki on the Caspian Sea. The Leprosarium is located in a semi desert 75 km from the Capital of Baku. It was at that time and still is nowadays. It is an adventurous trip across the semi desert in order to visit the leprosy patients there. Close to the leprosarium there is a small hill which is infested by poisonous black snakes that I saw in the evening on our way back to Baku, when they were moving in the sand.

Up to my arrival the patients had been treated with Dapsone. They were living in shacks formerly used for the oil workers of the Caspian Sea. The roofs contained holes so that the snakes could get into the shacks at night. We discussed this situation of the leprosy patients with the Minister of Health, Mrs. Semfira Godschiibaba when speaking about the possibilities to fight leprosy in this country.

In the year 2000, I returned to the Leprosarium Umbaki with my husband. We kept our promise to guarantee the supply for the leprosy patients. We also bought a new car, a Lada Niva, so that contact with the town of Baku was always possible. We handed over the car for the Leprosarium Umbaki to the Minister of Health as a present donated by the town of Dinslaken. At that time, Dr. Aliev Vidadi was head physician of the Leprosarium. In the year 2004, we visited the patients again. The leprologist asked for our help.

The Vice Health Minister, Dr. Bachschalieva Schachnaz was very helpful and even came to visit the leprosy patients of the Leprosarium with us several times.

By the year 2006, some of the shacks had been demolished and clean containers had been put at the patients’ disposal. Dr. Vidadi succeeded in talking to the oil workers’ families who then helped with renovation works.

In 2008, the car donated by the town of Dinslaken in 2002, broke down and could not be used any more. We then bought a stable Jeep in Baku so that the leprosy patients could continue to cover their needs of food, water and medicine. This car was also handed over to the Minister of Health. In 2009, the number of patients decreased continuously. They were living in clean containers. In the year 2015, there were only 10 leprosy patients in Umbaki. As they were all cured, I contacted the Minister of Health and asked him to take them back to Baku after 60 years of total isolation. Mrs Bachschalieva Schachnaz is still dealing with this matter.
Russia

Russia is the most important country of the former Soviet Union, also as far as leprosy is concerned. The centre to fight leprosy is the Hansen Centre in Astrakhan. It is now the central place for Russia and before that it was the central place for the whole Soviet Union (1/6 of inhabited world surface).

The Hansen Centre in Astrakhan is divided into three departments:
1. Russian Leprosy Research Institute
2. Hansen Clinic
3. Hansen Out-Clinic

The in-clinic treatment of patients is located in five different places:
1. Hansen Clinic Astrakhan (on the Caspian Sea)
2. Hansen Clinic Terski (Caucasus, on the Chechen border)
3. Hansen Clinic Abinski (Caucasus, on the Black Sea)
4. Zielonaja Dubrawa (Central Russia, near Moskow)
5. former Clinic Rostov Don (Caucasus) is now an out-clinic

The big out-clinic Rostov Don/Caucasus is now a small room, so it has not been an independent unity but belongs to a dermatological out-clinic.

The Russian Leprosy Research Institute in Astrakhan was founded in 1948 in Moscow, shortly after that it was transferred to Astrakhan, covering 300 beds. The reasons for this was that the area of Astrakhan is an endemic region.

My first visit to Astrakhan took place in 1998 on the occasion of the 50th anniversary of the institute. Professor Anatoli Juscenko was the Director at the time. After my first visit I took part in all following conferences: 2003 the "MDT Therapy Conference", during which I became an honourable member of the Leprosy Institute of Astrakhan. This conference was followed by a "Reha Conference" in 2005 and a "Jubilee Conference" in 2008. It was here that for the first time two languages were accepted: Russian and English.

In December 2006, Dr. Viktor Duiko became the Director of the Institute, as a successor of Professor Anatoli Juscenko and he introduced the following important changesto the Institute:

- The old Russian Leprosy Research Institute in Astrakhan opened its gates for worldwide leprosy work. Leprologists from India, Brazil, Scotland and Germany participated in the conferences there. Thus, contact with other leprosy institutes was made. Both Dr. Victor Duiko, Director of the Russian Leprosy Research Institute in Astrakhan, and his Representative of the Director, Dr. Vyacheslav Tsemba even visited Dr. Jaison Barreto at the Institute “Lauro de Souza” in Lima for two weeks, in order to discuss their common problems of leprosy work. In 2014 both doctors also visited Dr. Pai in Bombay in order to initiate a scientific exchange between their Institutes.
• Cured patients were allowed to participate in the conferences

• The patient has become a partner of the medical doctor during the treatment and healing process.

The Hansen Centre in Astrakhan is the only clinic in Russia without any form of isolation. It is located in the centre of the city.

One of the most important tasks of the Russian Leprosy Research Institute in Astrakhan is the training for all dermatological centres in Russia. They also offer training for physicians of all the Republics of the former Soviet Union. This Institute is most suitable for this task, since Russian is spoken in all countries concerned.

Although the political situation between these countries is sometimes delicate, the international leprologists are always in extremely friendly and supportive contact with each other.

Due to many international conferences in Astrakhan and numerous presentations and scientific exchange, guests from India, the USA, Germany and almost all countries of the former Soviet Union, we have become closer and have become friends, and finally after all these years of successful cooperation are like a family.

**Statistic Data: Number of patients:**

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<td>199</td>
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<td>Zielona Dubrava</td>
<td>157</td>
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Illustration 35 – Conference at the Institute Astrakhan, participation of Dr. Ganapati, Dr. Pai both Bombay Leprosy Project, and Dr. Lysbeth Duncan U.K.

Illustration 36 – Leprosorium Zielonaja Dubrava by Moscow: Russia, conversation with the Director of the Centre, Professor Goloszapos

Illustration 37 – Leprosorium Zielonaja Dubrava: together with patients in the meeting room

Illustration 38 – Leprosorium Zielonaja Dubrava: in the patient’s room

Illustration 39 – Terski Leprosarium: medical staff and guests: leprologists from other leprosy centres in Russia

Illustration 40 – Terski Leprosarium with a multibacillary (MB) patient
Countries on the Aral Sea

Kazakhstan

A film broadcast by the channel VOX in November 1993 was the catalyst of the Relief Action for leprosy people in Kazakhstan. I was invited to this far away country by a Kazakh family who turned up in my surgery at the time. In June 1994, the airplane took off from Dusseldorf including 70 cardboard boxes, towards Almaty, Kazakhstan, near the Chinese border and from there to the Aral Sea. The Director of the Leprosy Centre in Kazakhstan “Kasleprosarium” at the time, Dr. Ismagambetow Asylbieg, and his staff were very surprised that suddenly Europeans arrived with such a huge freight. They asked themselves, “Is it possible that people from different nations, religion and living on another continent are touched by our situation?” At the time, there were 116 leprosy patients in the leprosarium. Altogether there were 900 patients in Kazakhstan, all of them mutilated, disabled and suffering from severe impaired vision to complete blindness. The following relief actions were organised in Dinslaken every year. Thanks to the DAHW Würzburg, we were able to supply the Kazakh leprosy patients with MDT. This is how a good German Kazakh cooperation developed. It was also the basis for our 1st Leprosy Conference of Central Asian Countries in September 1999 in Almaty. This conference was organized in Dinslaken and financed together with the DAHW Würzburg. I am grateful that we have achieved the next important step.

As foundation members of the German Kazakh Society, my husband and I were invited by the Kazakh Ambassador in Berlin, Mr. Kairat Sarybay, together with 11 other people of the German delegation. We went on the first non-stop flight from Frankfurt to Astana, the new capital of Kazakhstan. I also had the opportunity to give in Astana a presentation on the topic “Leprosy – a worldwide disease” at the Medical Academy Astana. This was the beginning of my close contact with the University.

During the International Congress 2013 in Astana I was awarded a diploma of Honorary Membership of the Society of Kazakh Dermato Venerologists and Cosmetologists by Professor Gulnara Batpenova.

Within the 22 years of our Relief Action from Dinslaken for patients in Kazakhstan, a friendly relationship has developed. This connection has always been stable.
At the end of January 2016, we celebrated the World Leprosy Day in Kasleprosarium. Physicians from 17 out-clinic leprosy points in Kazakhstan took part. We exchanged our experience. At the same time I expressed: Leprosy nowadays referred to as “Hansen Disease”, has not been eliminated yet, it still exists! It is our duty to fight this illness, detect new cases, help leprosy people, cure them, rehabilitate them and pave the way for them towards a healthy life.

Currently, there are 450 leprosy people in Kazakhstan, 75 of them living in Kasleprosarium and the others are scattered across the country and treated as out-patients.
Uzbekistan / Karakalpakstan

In the year 1995, I took part in the World Congress of Polonia Medica in Tschenstochowa, Poland. It was my goal to get to know physicians of the countries former Soviet Union, who made up 50 % of all physicians taking part. I looked at the list of these 16 countries and noticed that the physicians from Uzbekistan were not included. I did not have any contact with them. However, I was lucky. Professor Tamara Muratova, an ophthalmologist from Tashkent and Scientific co-worker of the University, was present. By contacting her, we (my husband, my son who at the time was still a medical student - and I) received an invitation to Uzbekistan in 1996.
Professor Jesbojev, executive dermatologist and leprologist from Uzbekistan and Professor Muratova received us at the airport. We went to the University first, where we got detailed information about the leprosy people in the country by Mr. Jesbojev. The in-clinic patients of Uzbekistan were located in the southern part of the country near Samarkand in the Leprosarium Bachmal. At the time, there were 17 patients. Mr. Jesbojev told us about 140 out-clinic patients with whom the contact was not secured.

We visited the Leprosarium Bachmal, which was very small. Two doctors and 2 nurses took care of the patients, who were disabled and mutilated.

I noticed that one of the patients painfully distorted his face, obviously a leprosy reaction. I asked the doctor, why he did not give this patient Aspirin and Cortisone. He replied, “First you have to have the medicine and then you can give it to the patients”. The medicine we had brought from Dinslaken was still on the way to Karakalpakstan. But I was happy to have found this undersupplied country.

We knew from the WHO as well as from Professor Jesbojev that the centre of leprosy cases was located at the Aral Sea. So, we had already organized a transport of relief goods to the northern part of this country. The quantity of relief goods that we had sent by a 20 tons truck tractor train directly from Dinslaken to Nukus, (capital of Karakalpakstan) was huge and included: general medication, clothes, food, specific medication and MDT that we had got from the German Leprosy Relief Association (DAHW).

We reached Karakalpakstan by airplane.

This region was an autonomous republic at the times of the Soviet Union. When becoming independent, it became a recipient of Uzbekistan, with its own government (subordinate to the Uzbekistan government), its own language and very strict borders to Uzbekistan. 80 % of the country is covered by a desert, which is a reason for the difficult economic situation. Only some decades ago, fishing and fish processing were the main sources of income. But the cruel ecological catastrophe, shrinking of the Aral Sea due to the construction of barrages at the river Amudaria, leading to the Aral Sea, caused more incredible poverty.

The Leprosarium Krantau was located about 40 km from the Capital Nukus, in complete isolation. It was founded in 1933. Hundreds of leprosy people were living in Karakalpakstan at the Aral Sea. However, since its shrinkage, the number of patients has been decreasing. The patients lived there in clay huts from its foundation up to the year 2004.

At the time of our first visit in 1996, there were 106 leprosy patients in Krantau. Drinking water and usage water was delivered in tanks from the river Amudaria. There was no gas, electricity was unstable. There was no telephone connection, no bus or train connection.

And in this same country, an unbelievable miracle happened. Just before the International Leprosy Conference in September 2004, all the clay huts – habitation for leprosy patients – were demolished and at their place, a number of brick houses were built. On the occasion of this conference, I met Dr. Atajan Khamraev, the Vice Minister of Health. Our mutual cooperation during the next 12 years, in which Dr. Khamraev became Vice Chairman had beneficial consequences. The leprosy patients were taken from their isolation and brought to a suburb of the capital of Nukus, in a comfortable building with big roofed verandas and drinking water, electricity, gas, telephone and everything that was necessary. The rooms were supplied with complete medical equipment for the patients. The total number of leprosy patients is currently 250, and 56 of them are living in the leprosarium.

The opening of the Hansen Clinic was an important event for the town of Nukus with participation of the government and medical doctors of the whole town.

Despite the ecological catastrophe, the country was able to overcome the problems and fight lepromphobia.

What has been achieved in Karakalpakstan is an example not only for Russian speaking countries. It is an example for all countries worldwide being in a difficult economic situation and proves that people fighting with all their heart and soul to give former outcasts and despised people their dignity back, are able to achieve the unthinkable.
All this would not have been possible without the enormous contribution of Dr. Khamraev, former Minister of Health and now of Vice Chairman of Karakalpakstan. Therefore, I would like to express my thanks to him on behalf of all leprosy patients as well as myself.
Turkmenistan

During my stay at the Terski Leprosarium located in the Russian Caucasus in 1997, leprosy patients gave me a letter from the Turkmenian leprologist, Mr. Amangeldy Govshudov. In this letter, he asked me to come to Turkmenistan to see his leprosy patients. So, in May 1998 I arrived in Ashchabad for the first time together with my husband. We immediately felt at home due to the warmth and openness of the people. The medicine we had brought with us – MDT tablets, which had been donated by the German Leprosy Relief Association (DAHW) – were a great help for the leprosy patients there. According to Dr. Govshudov there were 126 leprosy patients at the time.

The stigma of this disease was extraordinarily distinct. The Leprosarium called Hodscha represented the worst examples of strict isolation. We were allowed to visit the leprosy patients there together with Mr. Govshudov. It was located in a no-man’s land along the mountain chain Kopetdag between Turkmenistan and Iran. From the Turkmenian border there was no official path to reach the leprosarium. We managed this earth road by off-road vehicle, the Turkmenian border being separated by barbed wire and alarm system and the Iran by the high mountains Kopetdag.

On the way there Mr. Govshudov strictly advised us, “It is forbidden to touch leprosy patients while examining them.” It was also not allowed to shake hands when greeting the patients. Mr. Govshudov told us that even his colleagues avoided him for fear of infection.
We also learned that we had been the only visitors from Europe ever to visit the leprosarium Hodscha. I only succeeded in examining four patients since the others were located in the north of the country at the Aral Sea. After a one-hour flight above the Kara-Kum Desert we arrived in Daschhowus. There were only out-patients, who had been taken to me for examination. We saw the other patients in their private houses and thus we could speak to their families and learn about their fears and worries. I particularly remember visiting a mother who lived in a small house together with her six grown-up daughters. I was shocked to notice that all seven women were suffering from leprosy. The quick extension of the disease was most probably based on the extremely poor living conditions. Together with Dr. Govshudow we put 16 new cases on MDT. Up to then they had been treated with the mono-therapy - Dapsone. I was also invited to give a lecture for the dermatologist at the University of Ashabad, which was received with great interest and elaborate discussion. After that the specific possibilities to fight leprosy were discussed with the dermatologist of the local clinics in the presence of representatives of the Ministry of Health and the WHO.

Our visit to Turkmenistan was followed by a noticeable attention and interest for the problems of this disease.

Unfortunately, six years later the President announced “Turkmenistan is free off leprosy”. So Dr. Govshudov finished his professional work in 2004 when he retired.

In 2009 he visited us in Dinslaken to stay in contact with us.

In July 2011 “The International Conference of Health” took place in Aschchabad. I was invited to give a lecture about the “Situation of leprosy in Turkmenistan”, by the head of the local WHO subsidiary, Dr. Bahtygul Karriyeva.

Still in Dinslaken I asked for permission also to fly to the north of the country to Dashowus and Boldumsas. This, however, was not considered as necessary since with regard to the local WHO point, the dermatologists from the northern part would also be present at the conference in Aschchabad., which was not the case.

Since that time I have not been in contact with this country.
Illustration 71 – patient

Northern of Turkmenistan Out-Patient


Illustration 73 - Northern-Turkmenistan: Patient (1998)

Illustration 74 - Northern Turkmenistan: Patient (1998)
Tajikistan

I had not envisaged flying to Tajikistan before the end of the century due to the state of war. Also, it was not possible to book flight tickets to Dushanbe from Germany.

However, I was concerned about the leprosy people in this country. I wrote a letter to the Minister of Health in Tajikistan asking for information about the number of patients as well as the form of leprosy. I thought about sending the necessary medicine there. A very friendly answer arrived quickly and also included an invitation as well as all the information I needed. Flight tickets were bought in Kazakhstan near the border to Tajikistan by the local leprologists, which was the only way to obtain flight tickets. We took six boxes of medicine – as always donated by the German Leprosy Relief Association, DAHW, Würzburg – and other medical items. The situation at the airport in Dushanbe and also in the hotel was extremely dangerous. Highly armed soldiers were everywhere. The Minister of Health, Mr. Ahmedov Ahmedovich, was obviously very concerned. He told us, “You are no allowed to go out on the streets on your own since I cannot guarantee for your safety. “We heard gunfire in the streets every day and every hour. Every day we were picked up by a delegation of both the government and the Dermatological Clinic. In the meantime, my husband had become ill. In these critical weeks, bravery was the most important challenge. We were taken to the Leprosarium Hanaka with our hearts beating from fear. The leprosy patients were surprised. I quickly wrote down all their needs, fears and complaints. We visited the Minister of Health daily, also to give a television interview for the whole of Tajikistan and the neighbouring countries. On our last day a contract between Tajikistan and Germany was finalized. Obligations of both sides were to be kept within one year. We signed, the Minister of Health Mr. Ahmedov Ahmedovich and myself. After my return to Germany I learned that I should not have signed this document. But this could not be changed. I had obliged myself to return to Tajikistan within one year and to take all medical items listed with me. My husband declared himself solidary to accompany me.

To guarantee our safety on our second visit to Tajikistan, we were locked in an apartment. The Minister of Health received us warmly and in a friendly way. “You have fulfilled all your commitments. This is wonderful” he told us. The leprosy patients were also very happy and so we became friends on our second visit to Tajikistan. We had purchased a Lada Niva to secure the connection of the leprosarium with the capital of Dushanbe.
The cooperation with the Tajik leprologist Dr. Azuzullo Qosimov is extraordinarily successful. He did his doctor's degree on “Leprosy in Tajikistan”. He also wrote a book about leprosy in Tajikistan and learned the English language, so he was able to follow training programmes in Ethiopia and India and to participate in international conferences.

The Tajik leprosarium has improved as well as both the general and economic situation.

In the year 2006, Dr. Kosimov organized an International Leprosy Conference in Dushanbe, which was presided by the Minister of Health, Mr. Ahmedov Ahmedovich. At the end, all WHO recommendations regarding leprosy work were accepted and made into guidelines for the following years in Tajikistan.

In 2013 together with Mr. Yohei Sasakawa I visited leprosy patients in the Leprosarium Hanaka. When making our farewell, he said, „So far I have visited 125 countries to check the situation of leprosy patients. What I have seen here is the best!”

I would like to express my thanks to the Minister of Health, Mr. Salimsoda and the chief Leprologist Azizullo Qosimov for the extraordinary commitment for leprosy people in their country.

In August 2014, an International Medical Expedition to Tajikistan took place in Pamir in the border region to Afghanistan. In this region of Gorno-Badakhshan was the highest prevalence of leprosy. Presumably, the Afghan border region also shows a high
prevalence of leprosy due to the risks of the infection. This was the reason for our
expedition, which was financed by the town of Dinslaken. We went for 1,400 km along the
border in Pamir by car and on an altitude of 3,400 m on earth-roads covered by fallen
rocks. We were constantly in telephone contact with the Ministry of Health in Dushanbe.
When one of the cars broke down, spare parts were brought by helicopter.

We were a group of 5 international doctors: Dr. V. Pai, Director Bombay Leprosy Project,
India, Dr. Moldagali Sotaliev, head leprologist in Kazakhstan, Dr. Azizullo Qosimov, head
leprologist in Tajikistan, Dr. Vyacheslav Tsemba, Representative of the Directors of the
Russian Leprosy Research Institute in Astrakhan and myself. The condition on which we
could do this task was courage, since there was a constant danger of death. Our motto
was “We are strong!”

I would like to express my thanks to the Minister of Health H. Salisoda, for his constant
support from the organization to execution of this expedition.
The year 2016 represented another highlight for leprosy people of the country, for the dermatologists and leprologists: an international conference with the participation of medical doctors from different countries and continents.

The result was excellent. A new schedule regarding the elimination of leprosy was established for the following years.

Kyrgyzstan
In the year 1999 I had planned to visit Kyrgyzstan. I landed in Almaty, the capital of Kazakhstan and was supposed that I could not to continue my trip by car from there to Bischkek, the capital of Kyrgyzstan. However, the border was closed and foreigners were not allowed into the country. Thousands of refugees were on the roads. It was a state of war. For this reason I could not get into touch with the leprosy patients in this country. My information of the leprosy situation of these patients was based on statements from Mr. Lachowitzki, a Kirghiz dermatologist who had participated in the Asian Leprosy Conference in September 1999 in Almaty. In his lecture he explained the situation of the 13 out-clinic leprosy patients at this time. Due to the economic crises, there was no specific treatment. There even was no Dapsone. In the context of Humanitarian Help, 3,000 Lamprene tablets were donated one-off from Germany in the year 1999. These tablets were given in form of monotherapy.

In case an in-clinic treatment was necessary, this took place in Kazakhstan, in Kasleprosararium.

There was no further contact with Dr. Lachowitzki, he did not respond to our correspondence. Only in the year 2003 did I succeed in contacting a dermatologist in Bischek, Dr. Kerimalieva Jipar, who promised to deal with leprosy patients. She received training in the Russian Leprosy Research Institute in Astrakhan and then she took part in the Therapy Conference 2003 and Reha Conference 2005 in Astrakhan as leprologist of Kyrgyzstan. However, in 2006 she resigned from this occupation for personal reasons. Since October 2008, there has been one successor, Dr. Gulkar Rysalieva. As well, she was also trained in the Russian Leprosy Research Institute in Astrakhan, but unfortunately, she was not in able to visit her patients in the mountains of Kyrgyzstan.

The present dermatologist of the country, Dr. Dilara Usupova, met Dr. Azizullo Qosimov, the Tajik leprologist on the occasion of the Leprosy Conference in Astana, Kazakhstan in spring 2015.

Dr. Usapova was immediately open for all international contacts. So we in Dinslaken organized and financed training in Bischek for all dermatologists from August 24. – 26.

Dr. Azizullo Qosimov, head leprologist in Tajikistan and Dr. Moldagali Seitaliev, head leprologist in Kazakhstan carried out this training programme in Bischek.

Dr. Dilara Usupova, Director of the Dermatological Centre of the Republic of Kyrgyzstan, expressed her thanks for this training programme to us in Dinslaken.

5. Specific Milestones

- From 1990 to 1999, we visited 11 of these countries at 23 locations. We found out about their specific needs and supplied MDT. The aim of these trips was to get into personal contact with leprosy patients and their staff, exploration of the patients’ situation and their supply with medicine and general items. Transports by big lorries from Dinslaken to these countries also secured the additional supply for the leprosy patients. Invitations of Russian speaking doctors to Dinslaken and to the DAHW were made for an exchange of information.
• 1999 – Together with DAHW Würzburg we invited all the leprologists we had visited in the previous 10 years to the I. Euro-Asiatic Leprosy Conference to Almaty, Kasakhstan (230 km off the Chinese border). These doctors were trained for one week. Mutual cooperation was stipulated with each single country for the following five years.

• 2003 – These leprologists were invited to the “Therapy Conference” to the Russian Leprosy Research Institute, Astrakhan. At that time, we were already a stable group of all leprologists former Soviet Union. The aim of the conference was the supply of all countries of the former Soviet Union with MDT at each WHO point located in the capital at the Ministry of Health. We asked Dr. Steve Lions in Geneva, Switzerland, for MDT forms and then translated these from English into Russian in Dinslaken. We returned the Russian version to Geneva, where it was accepted and stored in the Data Bank. It was then sent to all WHO points in Russian speaking countries by the WHO. The doctors were informed about the acquisition of MDT in their country on the occasion of the “Therapy Conference”.

• 2005 – The next meeting – “Reha Conference”, also into the Russian Leprosy Research Institute in Astrakhan. The goal of this conference was the supply of Modulan prosthesis (researched by Dr. Ganapati, Bombay Leprosy Project) for patients suffering from claw hands: disabled hands. The rehabilitation of these hands by means of Modulan is of great advantage. I brought 50 kilos of Modulan dough into the conference hall to demonstrate how to build prosthesis from this material and to distribute Modulan to the doctors of all the countries. Lectures – and not only practical training – were held for the leprologists. My booklet “Rehabilitation and Prevention of progressive deformation in Leprosy” was published in Russian language in Moscow and supplied to the doctors as a support during the treatment of leprosy patients.

• In order to secure highly qualified doctors, we organised and financed additional training for 12 doctors. In Bombay (BLP), the Director Dr. V. V. Pai for 6 doctors, (Dr. Kossimov, Tajikistan, Dr. Duiko, and Dr. Tsembo, Russian leprosy research Institute, Dr. Zamira, and Dr. Mazur Karakalpakistan, and Dr. George Arveladze, Georgia. In the Instituto Lauro de Souza Lima, Bauru Sp in Brazil, by Dr. Jaison A. Baretto, Chief of the Leprosy Section were trained 5 doctors: Dr. Naumov and Dr. Victor Duiko and Wiatceslaw Tsembo from Russian Leprosy Research Institute, Astrakhan and Dr. Sophiko Liluashvili from Georgia, and Dr. Azizzulno Qosimov from Tajikistan in Adis Abeba, Ethiopia, Africa.

• The “Atlas of Leprosy”, edited and published by Mr. Sasakawa, Tokyo, was translated into Russian for 1/6 of the populated area of the earth as additional training for the diagnostics of leprosy.

6. Our contact with WHO

Since 2010, I have been in touch with Sasakawa Memorial Health Foundation, The Nippon Foundation. The beginning of this contact was amazing. I got a letter from Mrs. Yamaguchi, Tokyo. She wrote: “I have seen your homepage on the internet. Therefore, I know that you are dealing with Leprosy in the countries of the former Soviet Union.” This was the beginning of an intensive mail exchange. Mrs. Yamaguchi was very interested in all my information concerning leprosy patients in the now independent states of the former Soviet Union. Half a year later I wrote to her, “I am flying to India tomorrow and therefore cannot answer your mails within the next weeks”. Within some hours I received her reply, “We will meet you in India”. We fixed a place, date and exact time. For both of us, this was an exciting and also very interesting meeting.

The interview took several hours and afterwards Mrs. Yamaguchi took a pile of papers out of her bag, which seemed familiar to me…. It was my website translated into English by Google. The aim of our meeting was to fix a mutual trip with Mr. Yohei Sasakawa, WHO Goodwill Ambassador. In her next mails, Mrs Yamaguchi let me know that she would visit me in Dinslaken in order to fix some other details of this mutual trip.

2012 – The airport of Moscow was our Meeting Point, followed by our flight to Astrakhan and a two-day Conference at the Round Table in the Russian Leprosy Research Institute in Astrakhan. The participants were: Mr. Y. Sasakawa, WHO Ambassador with his team, Dr. Sumana Barua, WHO Global Leprosy Program, leprologists from the Russian Institute and representatives from the most important states of the former Soviet Union. After that we examined patients in the clinic as well as outpatients in Astrakhan. Afterwards, we travelled through the Russian part of the Caucasus
with Mr. Sasakawa and his team to visit the leprosy centres Terski and Leprosarium Abinski. This was followed by a trip to Ukraine, to the Leprosarium Kutschurgan.

2013 – One year later, I travelled again with Mr. Sasakawa and his team: We visited Usbekistan – Karakalpakstan up to the former banks of the Aral Sea and then towards the Hindukush: Tajikistan – Duschanbe. We were received by the Minister of Health and then visited leprosy patients at the Leprosarium Hanaka.

7. Our contact with Bombay Leprosy Project

- 1986 - My first contact with Dr. Ganapati, Director of BLP We met in Würzburg, German Leprosy and TB Relief Association GLRA/DAHW. He participated in the Symposium on Multidrug Therapy in Leprosy. GLRA organizes this Symposium in cooperation with the Institute for Experimental Biology and Medicine, Borstel and the University of Würzburg. Many well-known leprologists accepted the invitation to come to Würzburg. “For the first time in the history of the fight against leprosy, the rigorous implementation of a treatment programme has succeeded in eradicating the disease from a whole area, namely Malta.” Prof. Dr. Dr. E. Freerksen.

- 1990 My first visit to Dr. Ganapati in Bombay Leprosy Project. I was staying in the Vimala Dermatological Hospital in Bombay in order to see new leprosy cases. However, I heard about the new method “Modulan” to be used in order to rehabilitate disabled hands. So I visited Dr. Ganapati together with my son Attyla. With great patience he explained to us how this method could help patients. I was absolutely enthused!

- 1993 14th International Leprosy Congress Orlando, Florida, USA. Approximately 1,000 leprologists from all over the world came together. The topic “The Actual State of Leprosy in Baltic States” (Poerst: Attyla Drabik, my son) attracted special interest. “I did not know that Leprosy also occurred in Europe,” Prof. Robert Hastings, Public Health Service, Laboratory Research Branch USA said. It was a great surprise to see that Dr. Paul W. Brand, California, USA, Founder of the Reconstruction Therapy in Leprosy, was present. There was a possibility to talk to many famous leprologists. I met Dr. Ganapati. He was holding four of his new booklets in his hand and was distributing them. They were all about Modulan and the rehabilitation of mutilated hands in leprosy. One of the highlights was the bestowal of the highest award for leprosy work: Damian Dutty for Professor Job, long-standing University Lecturer, Carville and Leprosy Centre Chettupattu. Those were very interesting and joyful days. On the 4th September 1993 we said goodbye and asked ourselves: What will the future bring? It was decided that the next Leprosy Congress in 1998 was to be held in Beijing. However, we did not see each other again in 1998. There was a priority for me – visit of countries of the former Soviet Union. Tajikistan – the Land of the Sun in the Hindukush – was in the middle of a cruel civil war. However, my husband and I decided to check the situation of the leprosy patients there. I will never forget the one week we spent there in the middle of the war. All of us – the leprologists as well as the Minister of Health – were in danger of death. On the first day when receiving us in the Ministry of Health, he said, “You are not allowed to go on the streets alone. It would be very inconvenient for my country if the media reported that two German citizens had been shot.” Still, we supplied the patients of the Leprosarium Hanaka with MDT and everything they needed urgently.

- 2008 17th International Leprosy Congress in Hyderabad, India. Meeting with Dr. Ganapati and Dr. Pai. Refreshing our old friendship. We decided to fight leprosy together. We started training leprosy for doctors from Soviet Union in Bombay. The same year, Dr. Azizullo Kosimow from Tajikistan went to Bombay to improve his knowledge regarding Leprosy. Our friends from Bombay also decided to visit us. Dr. Ganapati and Dr. Pai participated in the Conference in the Russian Leprosy Research Institute Astrakhan.

- 2009 Dr. Pai participated in the Conference in the Kazakh Leprosy Centre in Ksyl Orda.

- 2013 18th International Leprosy Congress, Brussels, Belgium. Dr. Pai was in our group of 12 leprologists. After the Congress there was a reception in Dinslaken City Hall by our Mayor.
• 2014 Our international leprosy expedition: Tajikistan / Afghanistan with daily danger to life. Our slogan was: “We are strong”

• 2016 Within the last three years I have visited Bombay Leprosy Project every year to see new cases and to accompany my colleagues from Russian speaking countries.

8. Summary

Looking back at the achievements of Leprosy Work Dinslaken today I am extremely surprised. Not even in my dreams would I have imagined the dimensions of this work.

Special facts have to be pointed out, especially in the countries of the former SU, which cover 1/6th of the inhabited Earth’s surface.

The existence of leprosy patients there was suppressed. According to the general public, these people were not worth dealing with. The interest of the people of Dinslaken was initially noticed with surprise and incomprehension, however, over the next years these marginal groups appeared in the awareness of the government and the general public. We were tolerated and gradually accepted with our activities for leprosy patients. People got used to our frequent visits, transport actions and the introduction of specific medicine to cure leprosy.

Thus, over the years from being strangers, we became guests and finally we became friends. We invited recognized leprologists from abroad and from other continents to Astrakhan. The gates of the Russian Leprosy Research Institute in Astrakhan opened its gates widely. A network with leprosy centres worldwide was the consequence and the Russian Institute gained importance.

Thanks to our support, medical doctors from the countries of the former SU could travel to countries with a high prevalence of leprosy to expand their knowledge regarding this disease.

The socio-medical situation of people affected and thus also their life improved considerably from year to year. The old leprosaria were renamed in „Hansen Clinics“. In Dinslaken, we are proud that our work has had such a positive and benedictory effect on the lives of the patients over 25 years.

During the International Dermatological Congress in Duschanbe, Tadjikistna in July 2016, Dr. Victor Duiko, Director of the Russian Leprosy Research Institute in Astrakhan announced for all participants, regarding the Leprosy Relief Work Dinslaken, „With your commitment, you have opened Russia and all the countries of the former SU to the world. Therefore, we are extremely grateful, also because now we are able to collaborate with you in leprosy work with all our strength”.

Thus, the retrospect of the results of Leprosy Work in Dinslaken has proved that we together with all supporters are able to give fundamental help to the poorest of the poor worldwide.

We shall continue!

9. Postscript

Statement of Dr. Atajan Khamraev, Supreme Council of the Republic of Karakalpakstan, Vice Chairman

“40 Years of Leprosy Work in Bombay and Dinslaken”

Before this terrible disease became curable, even before effective chemotherapy defeated leprosy, I and my whole generation had been schooled and had taken our doctor’s degree. Consequently, we merely saw only the terrible effects of this disease.

In the 60’s of the 20th century, not so very far back in the past, more than 20 per cent of the new leprosy cases found in the Soviet Union were patients of Karakalpakstan. However, leprosy elimination in Karakalpakstan is a wonderful example of today’s
achievements in medicine. There were times when people were afraid to visit our country because of leprophobia.

Nowadays however, our population has gradually recovered from the existence of this disease and our country is no longer associated with it. Some fear however, still lingers on. My first visit to the leprosarium of our country was in 2002 and the circumstances there left a deep impression on me. Dr. Romana Drabik has described this situation in this booklet.

Being the one responsible for Health in this country, I had then been obsessed by the idea of what to do with the leprosarium and how to improve the situation of the patients there. The majority of them were elderly and disabled. We started to renovate the existing houses and to build new ones. However, owing to our former attitude towards the disease, we were not able to change the way of thinking within a short time. So the leprosarium had to be situated at a certain distance from other people, isolated from the rest. Krantau was the ideal place.

After my meeting with Dr. Romana Drabik and Arkadius Drabik in 2004, my own attitude with regard to leprosy patients and the organizational questions involved changed completely by 180 degrees. During their stay at the Leprosarium, Dr. Romana and Arkadius greeted the patients and even embraced them like close family members.

Dr. Romana even knew most of them by name, she listened to their problems and she and her husband even lived among the patients for some time. In their presence I could not but become infected by their positive energy and their efficiency was to be envied. When I saw all this I became ashamed of our attitude to our patients. The most important thing I learned from Romana and Arkadius was that I have discarded all remaining feelings of leprophobia and any form of discrimination of these patients. From this moment on, the medical staff became part of the general medical staff and the idea of isolating leprosy patients is considered part of the past. With the support of the Government and especially of the Health Minister of the Republic of Usbekistan, we succeeded in building a different house for the patients in 2012, completely different from what it was before. On the outskirts of Nukus, the capital of our country, there is now an outpatients clinic and a clinic with all the equipment they need.

The endemic regions were checked up and contact persons examined by Dr. Romana and Dr. Waceslaw Tsemba in 2012.

Thanks to Dr. Romana, a promising local doctor was trained in leprosy in Astrakhan and later in India. She also took part in the International Leprosy Congress. All of this illustrates only a small part of what she has done to help the leprosy patients in Karakalpakstan.

From this booklet, I have learned much more of her work worldwide to eliminate leprosy and leprophobia, and I am convinced that this booklet will be a new impetus to fight Hansen Disease.

In future, there will be a better world because of persons with such experience and a good heart.

Furthermore, this booklet is an important argument for physicians to fight the stigma of this disease and an enormous contribution to change the way of thinking of mankind towards leprosy and the problems involved.

10. Acknowledgement

It is my wish to express my deeply felt gratitude to the large number of people who have contributed to initiate Leprosy Work in Dinslaken with great enthusiasm and devotion, with donations, encouraging advice and personal assistance.

My thanks also include the many children, teenagers and adults for their active help in carrying through the annual “Leprosy-March”.

Many thanks also go to the Mayor and the City Administration of Dinslaken for their kind support.

Furthermore, I owe great thanks to the World Health Organisation (WHO) for their support, to Mr. Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, Dr. Sumana Barua, and WHO Global Leprosy Program and to Dr. Steve Lyons, Dept. of Control of Neglected Tropical Diseases.
Last but not least, I thank my organization, GLRA, German Leprosy and TB Relief Association, (DAHW), especially the President, Mrs Gudrun Freifrau von Wiedersperg, and the Chief Executive Officer, Mr Burkard Kömm for the kindly cooperation.

Finally but from all my heart, I would like to say thank you to Dr. Victor Duiko, Director of the Russian Leprosy Research Institute in Astrakhan and to Dr. V. V. Pai, Director of Bombay Leprosy Project, for your invaluable collaboration.

However, to me the most important person to thank, is my dear late husband Arkadius Drabik. During 30 years, he was always at my side, supporting me in my daily problems with leprosy work, with great patience and never minding. Moreover, he accompanied me on each of my numberless leprosy expeditions. To him it was the most natural thing in the world.

11. Appendix

I, Azizullo Qosimov, am the director of the Leprosarium of the Republic of Tajikistan. I visited India twice, at the 17th International Leprosy Congress, 2008 and for the training in leprosy in Bombay (BLP) by Dr. V. V. Pay also in 2008. It was very useful for me and enjoyable to see and hear about different appearances of leprosy. I was amazed that leprosy is such a big problem worldwide.

The congress was held successfully and participants had the opportunity to compare the situation of leprosy throughout the world and ask questions to leading leprologists. The expert physicians brilliantly presented modern approaches for the management of patients with leprosy and strategies for elimination of leprosy. I personally became acquainted with such experienced experts as Dr. Luigi Pezzoni - Director of the National Center in Nalgonda. I had also an unforgettable meeting with Dr. Niranjan G. Nagpur, and together we consulted dermatological patients.

A very great impression for me was the meeting with Dr. R. Ganapati - Director Emeritus of the Bombay Leprosy Project and with his successor, current Director of the Bombay Leprosy Project Dr. V. V. Pai. They have great merits in the diagnosis and treatment of leprosy. They are not only wellknown in India, but also on other continents.

I had the pleasure to work and collaborate with them.

I would like to point out that Dr. Pai not only participated in meetings in India, but also in the Russian Federation, in Kazakhstan, and Tajikistan, my country, even in the high mountains of Pamir and in the border region to Afghanistan. I respect him very much! In addition, I would like to say that I think the problem of leprosy elimination in India is not only a problem for experts, but also for the whole society. We leprologists in Tajikistan have bilateral collaborative experiences. According to this in 2014 we organized in Tajikistan the first in Countries former Soviet Union “International Leprosy Expedition”. Physicians from Germany, India, Russia, Kazakhstan and Tajikistan worked together in constant face of death. Our motto was: “we are strong”. A positive point worth mentioning is, that leprologists all over the world will continue to work together and inform each other, which will serve to strengthen international relationships and awareness all around the world.
I express my gratitude to Dr. Romana Drabik, thanks to whom we were able to participate in the Congress of Leprosy and receive training in Mumbai Hospital. I also would like to note the huge contribution of Dr. Romana Drabik to collaborations between leprologists among former Soviet countries.

We are the Karakalpak Leprologists: Nuratdinova Zamira and Yuldasheva Manzura. Dr. Pai, Director of the Bombay leprosy Project (BLP) invited us to Mumbai to exchange experience and professional development. Every day we examined many patients, among them 3-4 new leprosy cases. We learned very much: to examine new patients, disabled patients in the slums Dahravi, also in in-clinics and out-clinics. Now we know how to rehabilitate, and the methods of rehabilitation. We learned to make smear tests and monitoring our patients. We saw many patients with leprosy reaction, learned to diagnose and to treat them.

We visited also Museum of Leprosy in Mumbai and we have an idea: we want to establish a museum in our country.

We are very grateful to Romana Drabik that she gave us the chance to experienced all that. It will help us with our work in Karakalpakstan.

Nuratdinova Zamira
On behalf of all staff and patients Leprosy Research Institute (Russia, Astrakhan) we express words of heartfelt gratitude of the German Leprosy and Tuberculosis Relief Association of care to patients with leprosy and personally to Ms. Romana Drabik for the opportunity to internship Russian doctors: Shats E. in ALETRT CENTER, Savin E., Duyko V. and Tsehba V. in Mumbai (India) and Brazil. We express our special appreciation for the invaluable assistance and support of experienced professionals in the fight against leprosy doctors A.Baretto (Instituto “Lauro de Souza Lima”) and V. Pai. (Bombay Leprosy Project).

Director of Leprosy Research Institute

V. Duiko