

**From:** Leprosy Mailing List <leprosymailinglist@googlegroups.com>  
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## **Leprosy Mailing List – May 6, 2025**

**Ref.:** (LML) Reconstructive Surgery and Physiotherapy in Leprosy Course. Sulawesi and Ambon, November 7–26, 2024

**From:** Wim Theuvenet, Apeldoorn, the Netherlands

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Dear Pieter,

We are pleased to report on our visit to Sulawesi and Ambon, Indonesia, November 2024.

### **Makassar, Sulawesi - November 7, 2024**

We started today by discussing patients. One of them is S—a truly remarkable individual! Due to a type 2 leprosy immune reaction that did not respond to Prednisone, he previously had extensive, deep wounds on both legs, which have thankfully healed with new medication (Apremilast). However, after a prolonged illness, his knees are now severely contracted in a fully bent position. The deformity is so severe that neither local nor Dutch medical professionals can determine a straightforward solution.

Theoretically, a surgical solution exists, but the risk of complications is high. This was extensively discussed with S. How motivated is he to undergo a potential surgery, followed by a lengthy rehabilitation of up to two years, in the hope that he can walk again? If successful, the operation would truly be a miracle!

Ton and Wim are volunteering, with LepraZending covering the course costs. But how do you organize aftercare? Could S undertake training to support himself independently after surgery? These factors are weighed carefully for every patient.

Fortunately, S is one of the most challenging cases, and other patients are easier to assist. Early tomorrow morning, we will travel with several patients to the Elim Hospital in Toraja, where additional patients will be added to the surgical list. Local surgeons there are highly motivated to collaborate and learn new techniques.

Ton Schreuders will train a large group of physiotherapists. With his extensive experience, he excels at this. From our privileged perspective, it's inspiring to face such meaningful challenges. It's amazing that so many people make this work possible in so many ways!

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## **Toraja, Sulawesi - November 11–17**

The rainy season has begun, and the rain pounds on the veranda roof.

A young boy with burn-induced contractures in his armpits, groin, and knees has withdrawn from surgery after his family expressed doubts. It's unfortunate, as his condition seemed surgically treatable with a high likelihood of enabling him to walk again.

On Sunday, we explored Toraja Utara (North Toraja). Local traditions include embalming the deceased with herbs and keeping them at home for some time before placing them in cave tombs. A figure resembling the deceased is then displayed in an open gallery. While initially striking, the sight has a warm and familiar feel.

Yesterday and today, we conducted training sessions in three parallel groups:

- **Dr. Diana Liben and Dr. Sri Wahyuni:** Educated healthcare staff on leprosy diagnosis and treatment.
- **Ton Schreuders:** Taught physiotherapy techniques for leprosy to about 30 paramedics.
- **Dr. Iswahyudi and Wim:** Performed surgeries on hands affected by leprosy alongside Dr. Francisca.

Some patients operated on last year returned for follow-up on their other hand, reflecting their trust in the results.

During the training, I (Ton) observed the treatment of J, a boy with paralysis in his right arm, initially suspected of leprosy. Further investigation revealed it was due to a previous dengue infection that affected his brain. This emphasized the importance of careful diagnostics.

The atmosphere is excellent, and the contrasts remain striking. The large Elim Hospital, run by the Church, plays a critical role in care provision. For claw-hand correction, we used the usual plaster splint, but the hospital lacked scissors or saws to remove it later. Fortunately, a dedicated rehabilitation doctor from Makassar visits every two weeks and can probably lend scissors from the hospital in Makassar. A problem solved with goodwill!

At the end of the day, we saw a touching case of an elderly leprosy patient with an ill-fitting below-knee prosthesis. She had to wear 20 socks layered over each other to get any support, resulting in a wound on her stump on one side and a severely infected foot on the other. She lives alone in a leprosy colony, where a group of fellow residents takes care of her. Unfortunately, her insurance will not replace her prosthesis for another two years.

We also saw other patients with deformities caused by past burn injuries.

One case was A, who had developed contractures in the armpit, abdomen, groin, and knees due to an old burn. Although extensive, these deformities seemed operable to us. However, his parents ultimately decided against surgery.

Another patient suffered severe burns six years ago, primarily affecting his left elbow, wrist, and hand. This challenging case was addressed by the surgical team led by Dr. Yudi, Dr. Francisca, and myself (Wim). The operation appears to have gone well; his hand has good circulation, normal sensation, and the fingers are already moving quite well. Rehabilitation still lies ahead, but Ton has left clear instructions.

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## **Makassar, Sulawesi - November 17**

Last night, after an 11-hour bus ride from North Toraja, our team returned to Makassar. Reflecting on the experience, it was a productive time there. Teaching was a challenge because basic knowledge about leprosy has entirely disappeared over the past 30 years. If we want to eradicate the disease, this knowledge must be regained.

Dr. Diana Liben and Dr. Sri Wahyuni, each with around 50 years of experience, trained a large group of doctors from 28 rural clinics (puskesmas) over the past week. Together, they identified several new patients suspected of leprosy, fortunately, at an early stage!

Ton worked with a mixed group of physiotherapists and other interested participants, teaching them basic knowledge that was otherwise missing. He covered exercises for stiff joints, making splints, and teaching pre- and post-operative exercises. This allowed us to perform surgeries on several hands affected by leprosy. A great team effort!

We are incredibly proud of LepraZending for enabling treatments that also address non-leprosy conditions, a fantastic way to reduce stigma! A donor has been found to provide M (the patient with "20 socks") with a properly fitting new prosthesis, requiring her to travel to Makassar twice.

There is still a long road ahead! However, it is heartening that care can be provided with such comprehensive attention to every patient. **Thank you, LepraZending!**

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## **Ambon - November 18–25, 2024**

We (Kerstin Beise from YDTI, Ronni from PerMaTa, Ton, and I) arrived in Ambon on Monday morning, November 18, after a short night in Makassar. We were met by Pak Aïs, a retired Wasor (former leprosy supervisor). He explained that there are significant numbers of leprosy patients in the Moluccas, but stigma severely hampers early detection.

Additionally, basic knowledge of diagnosing this disease, preventing deformities, and treating complications like immune reactions causing nerve damage, is currently lacking.

On Ambon, as in Sulawesi, this situation leaves us feeling quite disheartened. Some major leprosy organizations are increasingly focusing their funding solely on "chemoprophylaxis," a strategy using brief antibiotic courses for contacts of leprosy patients to curb transmission. Meanwhile, too many leprosy patients are left unsupported in the field.

We are proud that LepraZending continues to take responsibility by emphasizing education, reducing stigma, and tackling the wide range of issues faced by current leprosy patients every day.

On Monday afternoon, we saw a large number of patients and selected them for surgery.

In the following days, Ton focused on essential physiotherapy training, thoroughly documenting all abnormalities before surgeries, and preparing post-operative exercise schedules. He was assisted by Dr. Natalie, a highly dedicated rehabilitation doctor from Ambon, who, together with Maya, the physiotherapist, will also take on the aftercare!

Dr. Ishwayudi, whom we previously trained in Makassar, Dr. Sissi from a local hospital in Ambon, and I (Wim) were thus able to operate daily.

As I write this, it is already Thursday. This morning, Dr. Ishwayudi, Ton, and I gave a joint presentation on leprosy, nerve function disorders, preventing foot injuries, and surgical possibilities for correcting functional deformities caused by leprosy. This was presented to a large group of clearly interested doctors and nurses! Afterwards, we checked several patients who had previously undergone surgery.

Yesterday, we operated on M, who has been using prednisone for some time due to severe nerve pain in his elbow and also has a "claw hand." For him, we performed tendon transfers to treat the claw hand and decompressed the painful nerve near the elbow. This morning, he expressed his joy, stating that he no longer feels nerve pain and that sensation in his pinky finger is already improving!

This afternoon, more surgeries took place.

Every time we return to the Netherlands after such a working visit, we conclude that, despite its flaws, healthcare in the Netherlands is generally well-organized. Here, the sun shines, the food in the local stalls is excellent, and the people are remarkably warm, positive, and cheerful. However, there is also considerable bureaucracy!

For example, if you want to transfer a post-operative patient from one local hospital to another for physiotherapy, it must first go through an intermediate referral from a larger regional hospital. Many doctors work in multiple hospitals, requiring everyone to be highly "flexible" as key individuals are often "on the move," leading to frequent program adjustments.

One benefit is that you quickly learn to "de-stress" here—something we could definitely benefit from in the Netherlands!

We are convinced that leprosy can indeed be eradicated globally. There are several promising developments! However, the comprehensive care provided by LeproZending will likely remain indispensable for quite some time!

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## **CONCLUSION OF THE TRAINING IN AMBON**

**November 26, 2024**

The entire team departed two days ago for the Netherlands, Surabaya, and Makassar. I stayed a bit longer to be available for any issues with the previously operated patients, as this type of surgery is relatively unfamiliar.

A few minor issues have been reported, such as possibly overly tight casts and some loosening stitches, including from surgeries performed at the Elim Hospital in Toraja, Sulawesi. They do not have the proper scissors to cut the casts and instead soak them off, which is not the best solution! A pair of cast scissors has been found at Medic in Apeldoorn and will be sent to them.

We look back on successful training sessions in Sulawesi and Ambon, with enthusiastic participants and patients. As previously mentioned, a significant challenge remains in finding new patients at the earliest stage of nerve damage. There is a substantial stigma and a serious lack of basic knowledge and resources. This stems from the WHO's definition post-2006, suggesting that leprosy is no longer a "public health problem."

### **Some "bare" numbers to outline the current situation:**

WHO figures still indicate that Indonesia records 15,000–17,000 new leprosy patients per year, the third-highest number globally after India and Brazil.

Of all new patients in Indonesia, 90% have the multibacillary (MB) form, which is contagious. Of these, 8.9% are children, and approximately 30% already have some degree of nerve damage.

Across the Moluccas in 2023, 535 patients (142 of them in Ambon) underwent treatment with medication to kill the leprosy bacteria.

We can neatly summarize these numbers in Excel sheets, crafting impressive "new" strategies that, while decades old, appear innovative with a modern twist. However, what no Excel sheet can capture is the despair and exclusion many patients face after receiving their diagnosis. It requires moving "away from the desk" to listen to personal patient stories, giving the statistics the essential meaning they deserve!

That was cathartic!

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**After the training sessions, what remains is satisfaction.**

Dr. Diane Liben (known as “the Mother of Leprosy Patients in Indonesia”) and Dr. Sri Wahyuni imparted knowledge on diagnosis and treatment to a large number of rural clinic doctors. Ton Schreuders (worthy of platinum recognition for his consistent contributions) shared his expertise on nerve damage in leprosy and physiotherapy possibilities, enabling Dr. Ishwahyudi (from Makassar) and me (Wim) to perform a series of operations with improved outcomes.

There remains a feeling that we wish we could have done much, much more.

Thanks to the patients who entrusted us with their care, to Kerstin Beise (YDTI), who tirelessly prepared everything like a spider in its web, to the members of PerMaTa (young former leprosy patients) who assist in early patient detection, and to the numerous staff in all host hospitals who wanted training and offered their hospitality.

And “last but definitely not least,” to LepraZending Nederland, which made all this possible.

Indeed:

**“No leprosy patient should be left out in the cold!!”**

**Thank you!!!**

Kerstin Beise (YDTI), Pak Kadri (PerMaTa), Ton Schreuders (Physiotherapist), Wim Theuvenet (Plastic Surgeon), LepraZending Nederland

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**LML** - S Deepak, B Naafs, S Noto and P Schreuder

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