PATSOGOLO CP FOUNDATION

Historical Growth Summary

2022 – 2026

A summary of the organisation's evolution from a single clinic to a four-site, multidisciplinary foundation.

Mangochi District, Malawi· “No child left behind”

Overview

Patsogolo CP Foundation traces its roots to a single physiotherapy-led clinic for children with cerebral palsy (CP) at Malawi Children's Village. Over four years, it has grown into a four-site, multidisciplinary programme spanning clinical care, awareness and advocacy, health worker training, assistive device production, and research.

Phase 1: Origins (2022) A Physiotherapy Clinic

- CP care in Mangochi began as a physiotherapy-only service, run out of Malawi Children's Village.
- Cerebral palsy was recognised as the leading cause of childhood physical disability in the district, but care was fragmented: no integrated approach existed for the medical, nutritional, and developmental needs of these children.
- Community understanding of CP was and remains, in parts shaped by stigma and misconception (CP frequently attributed to curses or "something gone wrong," per 2023 community interviews).

Phase 2: The Multidisciplinary Pilot (February 2023)

This is the pivotal moment in the organisation's history: the clinic was redesigned as a multidisciplinary outpatient service, combining physiotherapy, nutrition, medical care, and health education under one roof modelled on the ICF (International Classification of Functioning, Disability and Health) framework.

Key baseline findings from the 2023 pilot

42%	40%	92.2%	59%
of attending children had epilepsy	had moderate-to-severe malnutrition	were wasted 35× the national average	increase in attendance after integrated care

- 20 health centres and 2 community hospitals were trained (1 Clinical Officer/Medical Assistant + 4 Health Surveillance Assistants each).

- Community health education sessions reached 73 stakeholders (chiefs, counsellors, religious leaders, teachers, traditional healers) across 5 villages, surfacing widespread stigma and the financial/isolation burden on caregivers, predominantly mothers and grandmothers.
- A validated Quality-of-Life questionnaire was administered to 62 patients, and 7 caregiver focus groups were held, early evidence-gathering that shaped later caregiver-support and drama-play initiatives.
- Local device production began: 21 CP chairs, 21 standing frames, 19 rollators, 3 tricycles, 3 wheelchairs made with a local carpentry workshop.

Funding at this stage came through Cerebral Palsy Africa, with the project run under the KUHES Family Medicine Department and Mangochi District Hospital's Physiotherapy Department.

Phase 3: Scaling to Four Sites (2024)

The 2024 Wilde Ganzen proposal marked the shift from pilot to structured, multi-year programme, organised into 7 activity areas: health worker training/mentorship, continued integrated clinics, nutrition care improvement, home-based rehabilitation (via community rehabilitation volunteers), device production, caregiver support groups, and evaluation.

- A third clinic site was added at Malembo, bringing the total to the four-site model (Malawi Children's Village, Mangochi District Hospital, Njereza, Malembo) that has persisted since.
- Our first World CP Day was marked, bringing children, caregivers and community leaders together for the first time.
- Our caregiver-led drama-play group was formed, now central to how we reach communities across Mangochi District.
- Nutrition interventions were formalised: Likuni Pala (local fortified porridge) for moderate malnutrition, RUTF referral pathways for severe cases.
- Home-based rehabilitation was piloted with 5 community rehabilitation volunteers, each supporting 4 families (20 families total).

Phase 4: Networks and Systems (2025)

2025 was a year of institution-building rather than just service expansion, under the Enablement Foundation/Wilde Ganzen partnership.

- A CP/Neuro-Developmental Network meeting was convened with ~50 participants from government, non-government, hospital, and community-based rehabilitation (CBR) organisations, covering early identification, clinical care, research, and advocacy.
- Our electronic patient records system was introduced to track follow-up, food supplement needs, and clinical data across sites.
- The EDACS (Eating and Drinking Ability Classification System) validation project began — translating and validating an international feeding/swallowing assessment tool for the Malawian context (originally proposed to the Dutch Albert Schweitzer Foundation, co-funded with Wilde Ganzen; total budget €13,453).
- The CP cookbook, in development since 2024, was finalised and printed.
- Our second World CP Day was marked, building on the momentum of the first.
- Early identification expanded into the maternity and nursery wards — reaching mothers of at-risk newborns directly at the point of birth (Mangochi Hospital sees ~1,200 deliveries/month).
- Outreach began to Tiyende Pamodzi, an existing rehabilitation-only provider, as a potential network/mentorship partner.
- Governance groundwork was laid for what would become Patsogolo CP Foundation, with a Board of Trustees and management team taking shape.

Phase 5: Diversification (2026 to date)

2026 is the year the programme both formalised its identity as Patsogolo CP Foundation and diversified its clinical and research scope substantially.

Clinical expansion

- An Autism and ADHD clinic launched 28 April 2026, following training of 9 health workers (physiotherapy, nursing, mental health, nutrition) by an occupational therapist — a new diagnostic category added to the CP programme's scope.

- Formal partnership established with MAP (Malawi Against Physical Disabilities) to train local artisans and improve locally made assistive devices.
- Modified feeding utensils distributed to 25+ children so far in 2026, shared with the CP clinic at Queen Elizabeth Central Hospital (QECH).

Research and publication milestones

- The CP cookbook was published in Field Exchange (issue 77, 2026): "Developing a practical cookbook for children with cerebral palsy in Malawi" subsequently adopted into UNICEF's disability feeding resource bank, with interest from health workers in Tanzania and India.
- The validated Malawian Cerebral Palsy Quality-of-Life (CP QoL-Child) questionnaire was accepted for publication in the Malawi Medical Journal (July 2026) the first tool of its kind validated for the country.
- Our first PhD trajectory began, undertaken in collaboration with academic and hospital partners to examine our district-level CP care model in depth.
- A study on disability prevalence in malnutrition wards, and research into caregiver/health-worker experiences of accessing care, are ongoing.

Caregiver empowerment

- The caregiver-led drama-play group grew to 12 members (including caregivers from Malembo), trained by Together Act Now, producing six productions carried through monthly physical and radio performances.
- Caregivers moved from passive participants to active co-creators of health education materials, tailored to their literacy levels and needs.

Networks, advocacy and collaboration

- The Neuro-Developmental Disorders Network was formalised with KUHES Rehabilitation Department, QECH, Zomba Central Hospital, and Fount for Nations positioning the group as a national resource/training centre for NDDs in Malawi.
- Monthly radio programming now reaches 8 districts, broadcast twice weekly and archived as a podcast; a caregiver-developed radio drama was added in 2026.

- School inclusion work expanded: 2 private daycare centres and 1 government primary school assessed and given basic teacher training; an advisory role established at a newly opened special-needs daycare in Mangochi Boma.
- New collaborations with other hospitals and academic institutions began, extending our clinical and research reach beyond Mangochi District.

Sustainability

- A detailed Year 1 Plan of Activities (August 2026–July 2027) sets targets across the organisation's programme areas.
- Some planned 2026 activities, including wheelchair provision for 11 identified children, are currently seeking funding support to move forward.
- Local fundraising has begun including a donation from Dossan Trust and sales of the cookbook and feeding devices alongside Wilde Ganzen fundraising training for team members.

Growth at a Glance

Year	Milestone	Scale
2022	Physiotherapy-only CP service begins at Malawi Children's Village	1 clinic site
Feb 2023	Multidisciplinary clinic pilot launched	200 children; 59% attendance increase
2023	Health worker & community training	20 health centres, 2 community hospitals, 73 community stakeholders
2024	3rd clinic site added (Malembo); first World CP Day; drama group formed	4 clinic sites

Year	Milestone	Scale
2025	CP Network formed; electronic patient records introduced; EDACS begins; 2nd World CP Day	~50 network participants
2026	Autism/ADHD clinic; first PhD trajectory; two journal publications	400+ children; national/international research recognition

The Throughline

Each phase built directly on evidence gathered in the one before it: the 2023 baseline data on malnutrition and epilepsy justified the multidisciplinary model; caregiver focus groups from 2023–2024 shaped the dramaplay and co-creation approach used today; and the collaborations and research partnerships built in 2025–2026 are extending that evidence base further. What started as a single physiotherapy clinic has become a foundation with a validated research base, national academic partnerships, and a four-pillar programme model — while remaining rooted in the same district-level, community-embedded approach it began with.

> ***"No child left behind" isn't a slogan added later. It's the reason the clinic changed shape in the first place.***
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