



# **PARKINSON PATIENTS SUPPORT ORGANIZATION ETHIOPIA (PPSO-E)**

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HEAD QUARTER: ADDIS ABABA, ETHIOPIA**

**S I N C E 2 0 1 1**

## **Background of the PPSO-E**

Parkinson Patients Support Organization Ethiopia (PPSOE) was founded to enable Parkinson's patients and caregivers in Ethiopia to lead a quality life. Established in 2011 by Kibra Kebede, a dedicated Parkinson's disease patient, PPSOE aims to create a supportive and informed community where individuals affected by Parkinson's disease receive the care and support they need.

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### **VISION**

Enabling Parkinson's patients and caregivers to live a quality life.

### **Mission**

To create a supportive and informed community where every individual affected by Parkinson's disease in Ethiopia receives the care and support they need to lead a quality life.

# Stage 1: Establishment (2011-2012)

## Founding Motivation:

**Founder:** Kibra Kebede, who established PPSOE in 2011 driven by her personal experience with Parkinson's disease. Her journey revealed critical gaps in support, including misinformation, stigmatization, misdiagnosis, and inadequate patient and caregiver support.

## Early Challenges:

**Resource Constraints:** Kibra initially financed employee salaries for five months. A significant loan of 1,363 USD from the Protestant Agency for Diakonie and Development (PADD) for Bread for the World enabled office space rental and the initiation of operations.

**Limited Capacity:** Early activities focused on awareness and disease management training, with minimal practical support capabilities.

## Initial Activities:

**Awareness Raising:** Initiated public education campaigns about Parkinson's disease for both the general public and healthcare providers.

**Early Expansion Efforts:** Began broadening scope to include care and support, and capacity-building initiatives.

## Stage 2: Growth and Development (2013-2016)

**Expand Service:** Drug support, physiotherapy, and nursing care for bedridden patients.

**Healthcare Professional Training:** Training medical professionals to enhance their diagnosis and treatment approach

**Media Engagement:** Training journalists to boost public awareness and understanding of Parkinson's disease.



*Disease Management Training*



*Physiotherapy for the patients*

## **Key Programs and Impacts:**

**Awareness Raising:** The awareness-raising efforts, including TV and radio campaigns, distribution of educational materials in Amharic, and training journalists and religious leaders, significantly increased public understanding of Parkinson's disease, reached diverse audiences across communities, and empowered influential figures to disseminate accurate information, thereby fostering a more informed and supportive society.

### **Capacity Building:**

- Trained over 600 patients in Parkinson's disease management and provided physiotherapy, and speech therapy significantly enhancing their self-management capabilities, and contributing to their physical and mental health.
- Trained over 200 caregivers to enhance their ability to assist Parkinson's disease patients with knowledge and recommended approaches.
- Trained more than 500 medical professionals to improve their diagnosis skills.

### **Care & Support:**

- Drugs, wheelchairs, walkers, oil, flour, nursing care services for bedridden patients, and patient-friendly toilets, greatly improved the quality of life for patients, enhanced their mobility, and ensured continuous, compassionate care in a comfortable environment.

## Stage 3: Maturity Period (2017-2023)

### Service Diversification:

**Comprehensive Support:** Expanded different services.

**Drug Inclusion:** Successfully advocated for Parkinson's medications to be included in the government's essential drugs list.

**Caregiver Empowerment:** Implemented a caregiver empowerment package, providing vocational training and assistance with business startups for 30 caregivers.

### Regional Expansion:

**Broadened Reach:** Started services beyond Addis Ababa to regional areas.

### Capacity Building:

**Training Programs:** Continued extensive training for healthcare professionals, patients, and caregivers.

# Major Achievements and Impacts:

- Increased awareness among patients and caregivers about Parkinson's disease and its home management.
- Mobilized professional volunteers.
- Media entities started disseminating PD-related news and information on their initiative.
- Provided home care services regularly for bedridden patients.
- Constructed PD patient-friendly toilets.
- As a result of advocacy, PD drugs were included in the government list of essential drugs.
- Increased the social engagement and participation of Parkinson's patients.
- Decreased misdiagnosis.
- Enhanced coping capacity of PD patients and caregivers to live with the disease.
- Prepared policy briefing to integrate Parkinson's Disease into the Ethiopian primary healthcare guidelines and presented it to stakeholders.

*Dr's Training in Durame town*



*Disease Management Training in Durame*



*Homecare service*



*Home Visit*



*Religious leaders' training*

## Challenges:

- Due to the lack of a prevalence study, the government doesn't pay attention to Parkinson's disease in the national health strategy.
- Financial constraints hinder the effective implementation of projects.
- Inability to reach regions due to resource shortages.
- High cost of drugs and essential materials due to market inflation.

PPSOE require significant support and fund to address key challenges in Parkinson's disease advocacy, from donors and research institutes:

1. **Raising Awareness:** Intensive awareness raising and continuous media work are required to raise community awareness.
2. **Advocacy for National Health Strategy Inclusion:** PPSO-E successfully advocated for the inclusion of Parkinson's disease in the primary health care guidelines, but to implement this, PPSO-E needs to support the Federal Ministry of Health.
3. **Reaching Underserved Regions:** PPSOE needs to expand services to regions.
4. **Mitigating High Drug Costs:** PPSO-E needs support to ensure continued access to affordable treatments.
5. **Prevalence study:** A prevalence study is crucial for addressing Parkinson's-related challenges because, if the number of Parkinson's patients and the disease burden are known, it becomes easier to lobby the government. Therefore, PPSO-E urgently requires support from donors and research institutes to assist us in this effort.



*Experience sharing*



*Project launching workshop*



*World Parkinson Day*



*Caregivers' empowerment*



*Policy briefing workshop*

## Patient Success Stories

- **“From the Trembling Woman to a Source of Hope” – Mrs. Alemenesh:** Mrs. Alemenesh, once a dynamic businesswoman, faced severe depression and social isolation due to Parkinson’s disease. Known as “the trembling woman” in the market, she struggled with a lack of support. PPSOE’s assistance transformed her life, renewing her spirit and providing a sense of community. She now actively shares her experiences to help others, demonstrating how PPSOE’s support restores dignity and purpose.



- **A Journey of Resilience – Asalif Tilahun:** Diagnosed with Parkinson’s disease in 2018, Asalif Tilahun joined PPSOE for support and education. The organization’s resources and community support helped him manage his condition effectively. Asalif has become an advocate for Parkinson’s awareness, sharing his story and educating others about the risks associated with herbicides. His journey underscores the importance of community support and proactive disease management.



## **Stage 4: Future Plans and Strategic Vision (2024 Onwards)**

### **Expanding Reach:**

**National Prevalence Study:** Plan a study to better inform policy and strategy.

**Extend Support Programs:** Aim to reach more patients across Ethiopia.

### **Strengthening Policy Influence:**

**Healthcare Policy Advocacy:** Focus on enhancing national healthcare policies for Parkinson's patients.

### **Fundraising and Resource Mobilization:**

**Secure Additional Funding:** Necessary for program delivery enhancement and expanded reach.

### **Role of Donors:**

**PAAD and Other Donors:** Essential for achieving future goals, including the national prevalence study and expanded services.



## Call to Action

- **Community Engagement:** Encourage support through donations, volunteering, or advocacy to help expand the reach and enhance programs.
- **Reaffirmation:** PPSOE remains dedicated to improving Parkinson's patients' lives by advancing programs, raising awareness, and advocating for better policies.

## Gratitude

- **Acknowledgment:** Heartfelt thanks to all supporters, especially PAAD, for their instrumental role in the organization's achievements and positive impact on Parkinson's



# Staff



# 2022 “Bego sew” Award Winner



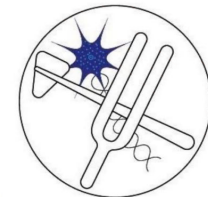
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