

first wealth is health



ACTIVITY REPORT 2009 - 2011

Fr John Kolkman Sickle Cell Foundation

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Vision

Restore wholeness to the sickle cell person and family to live a normal and productive life

Mission

Ensure the early detection, proper management and treatment of sickle cell disorder;
Promote and improve the quality of life of sickle cell patients;
Provide outreach, awareness, case management, screening, nutrition and counseling services.

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From the Founders

Sickle cell disease in Cameroon, may not be widely known by its clinical name, but its manifestation, social, emotional and physical pain are well known and felt. More than 100 years since the first laboratory description of the disease, there is no cure for or vaccine against it. Its burden on affected and infected persons and families continues to increase. Ignorance of the disease is high. There is a need to educate the population and dispel the myths. Stigmatization, discrimination, and the threat to the stability of family life continue to accompany the diagnosis of a child with the disease. Advances in the understanding and management of the disease have led to improved life quality for affected persons and an increased life span. However, programs and services, when and wherever they exist, are not easily or readily accessible and affordable to those who need them.

Human Suffering is part of the mystery of human life. It offers an opportunity to share in the suffering and healing ministry of Christ. We are not capable of curing sickle cell disease, but we are capable of caring for each person suffering with sickle cell. In 2007 FJK embarked on a journey of care, full of challenges, into the sickle cell community of Cameroon. For five years, we have been an intricate part of the sickle cell community, serving more than 300 families through direct services and events. Through community initiatives, workshops, seminars, newsletters and conference, we have reached more than 2,000 persons in the sickle cell domain. Our Outreach Program has made exploratory initiatives beyond Bamenda. We now have representatives in Limbe, Yaounde and Bafoussam.

August 2011 was a remarkable high point as we organized the First International Sickle Cell conference in Bamenda, which brought national attention to, support for and exposure of the sickle cell story. The conference was the highlight of activities marking the 2010-2011 Sickle Cell Awareness year in Bamenda, declared by the Foundation and endorsed by Dr Ndiforchu, Northwest Regional Delegate of Health.

Each year we continue to grow in our clinical services, Outreach, support capacity and the number of collaborators or partners.

We are appreciative of the support that has been awarded the foundation from various individuals, and through its collaborators and partners especially Ministry of Public Health, Archdiocese of Bamenda, NWR Regional Delegation of Public Health, Predestined, Inc., and the Servants of Mary in Ladysmith, Wisconsin, USA.

On behalf of the Sickle Cell Community of Cameroon, we thank God for your prayers and support of our common vision and mission. We have all you and your loved ones in our every prayer intention.

Rev Michael & Florence Ayakor Neba

FJK Founders

FJK Foundation Genesis

In 2006, the Neba Family planned to return to Cameroon for a Thanksgiving Celebration following the Deacon's ordination in 2004. Part of the plan was to raise money during the occasion to construct a public hall - the proceeds from its usage would be used to assist sickle cell patients. On discussing with Christian Cardinal Tumi,



he suggested a clinic would better serve the needs of the patients than a hall.

Thus, the foundation was conceived on January 1, 2007, and launched in Bamenda over a two day period: January 27th at the St Joseph's metropolitan

Cathedral and St Joseph's Parish, Bafut. Over 5,000 people were in attendance and the sum of CFA 1.2 million was raised.

Christian Cardinal Tumi - Archbishop Emeritus of Douala, Archbishop Cornelius Fontem Esua of Bamenda, and Archbishop Simon-Victor Tonye Bakot of Yaoundé were principal celebrants of the historic launching ceremony amidst royal and honorable dignitaries: Fon Abumbi II of Bafut, Fon FOZO II of Awing, Chief Wanki of Mambu; Hon Martin Chungong Ayafor; Mrs. Grace Mba of EDUCARE.

In 2008 HR Chief Ntoh of Bawum commissioned the Quifor of Bawum to designate a site for the construction of a Sickle Cell Center and Clinic. The Chumgom family was generous enough to offer the site where the center is under construction.

Father John Kolkman



John Kolkman was born in Groenlo, The Netherlands, on 17th November 1936. At the age of fourteen, he joined the Mill Hill Missionaries as a Seminarian. Ordained priest on 7th July 1963, he spent 21 years of his priestly ministry in Cameroon. He served in Bafut, Fiango and Kumbo.

While returning from Mbekunyam, a Mission out-station of his Parish, he died on the way on 11 October 1985. He is buried in Bafut, the Parish where he began his missionary service in November 1964. He was 49.

Father Kolkman died in harness, serving the people of God for which he had consecrated his life. A man of great ambitions and undertaking, nothing was ever too much for him. His passion for the physical and spiritual wholeness of the human being led him to build a church and health center in each of the mission outstations under his pastoral care.

To his tribute, the Father John Kolkman Foundation is established to continue this passion with focus on sickle cell patient care.

Core Values

Human Dignity: All are entitled to care, attention and respect.

Common Good: Concern for the well-being of the wider community – beyond self.

Solidarity: Our full potentials are realized when we share our lives with others and cooperate on projects that hold the promise of mutual benefit.

Compassion: Expressed concern for the well-being of the person and family.

Accessibility: Bring care to the community where it is needed.

Community Life: Our experience, environment and those we encounter help shape the decisions we make each day.

Accountability: Take responsibility of every action; review the past in anticipation of the future.

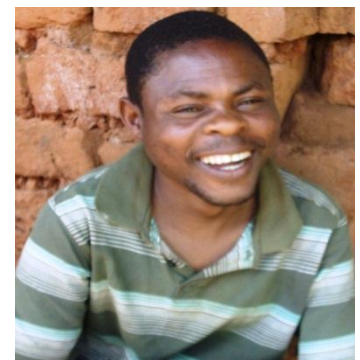
Family: Recognize the family as the primary caregiver, center of strength and support for the human being.



Our Creed

We believe that:

- Each person has dignity because all are made in the image of God
- Human life is a precious gift from God; we are stewards of this gift
- The wholeness of the human person constitutes the physical, psychological, social and spiritual dimensions.
- Clients and staff enter into a relationship that requires mutual respect, trust, honesty and integrity.
- Suffering is a part of human life and presents an opportunity to share in the suffering and healing ministry of Christ.
- We are not capable of curing sickle cell disease, but are capable of caring for each person suffering with the disease. We therefore take to heart and strive to maintain our Core Values as stated.



Services and Programs

Outreach, Awareness and Education

Our first face to face encounter was in March 2009



Balikumbat participants



Donated Supplements in 2009

- 2009: First Sickle Cell seminar was held Small Mankon, Bamenda. 200 participants attended. We donated 5,000 US dollars (2.5 million CFA) worth of folic to more than 100 sickle cell persons. Each received a year's supply. We also served a few families in Balikumbat.
- 2010: Workshop in Bamenda in October marked the beginning of the sickle cell sensitivity year in the Northwest region. The Regional Delegate of Public Health chaired the workshop. More than three hundred people were in attendance. The workshop initiated the beginning of the public health educational campaign for sickle cell awareness.
- 2010: In November we began the monthly publication of a sickle cell education newsletter "Eye Opener". 100 copies were circulated. Publication stopped in April 2011 due to lack of funding.
- Introduction of Hemoxide - medical food for sickle cell crises prevention. The supplement has proven to be an effective tool in sickle cell crises prevention. However, affordability is an obstacle to many who need it. About 30% of the cases that enrolled in the management program have dropped because of cost.
- 2011: Organized the First International Sickle Cell Conference in Bamenda that drew over 800 persons from around the country and renowned international sickle cell experts, <http://sicklecellreport.jkolkman.org>.
- A number of educational programs have featured on local radio stations in the northwest Region and including CRTV.
- Sickle Cell Awareness presentations were made to secondary schools and churches in and around Bamenda municipality.
- We produced a sickle cell informational brochure that is given out at presentations and to communities on request.

Infrastructure Development - Sickle Cell Center

The Sickle Cell Center, under construction, is located in the Bafut Health District, at Bawum, Bafut. Phase 1 of the construction began in 2010 and was completed in 2011. The Servants of Mary Sisters in Ladysmith Wisconsin provided the initial funds of 25,000 USD. The Center is designed to house a library, pharmacy, canteen, chapel, bathrooms, five exam rooms, and bed units, consulting rooms, a laboratory, reception area, a crisis management section, a conference room and counseling units. There is more than one hectare of land for expansion.

2008 - Quifor of Bawum under the direction of His Royal Highness, Chief Ntoh allocated a piece of land for constructing center. The Chumgom Family

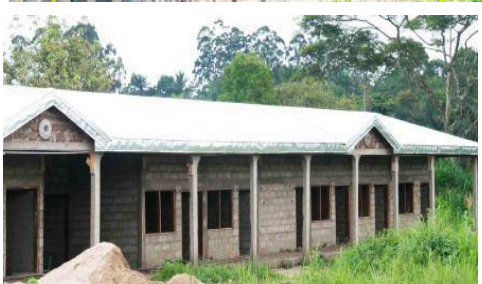
collaboratively donated the land.

2009 - Pope Benedict XVI blessed the foundation stones in Yaounde, during his visit to Cameroon in March. Archbishop Cornelius F Esua presented the stones.

2010 - The construction ground was broken in February and construction began shortly afterwards.

2011 - Phase I - Elevation, roofing, shutters, etc. completed.

Phase II comprises: Plumbing, wiring, interior finishing and furnishing, landscaping, construction of an access road, and readiness for use.



Clinical Services and Surveillance

- Clinical Services began In March 2010 in Small Manson in a classroom offered by the Parish. 50 clients were registered. Operation once a week for two hours, the number of clients rose to 105 by the end of the year.
- The clinic currently operated out the Regional Hospital Bamenda, in a building made available by the Ministry of Public Health through its North West Regional Delegate. It is opened Monday to Saturday from 8 am to 4pm. More than 300 families have received clinical and support services from the Foundation. From March 2010 to October December 2011
- We have a staff of three, but lack a full time nurse, medical doctor and laboratory technologist, equipment and supplies.
- Our nurses have made the following observations from those taking the supplement, Hemoxide: some who came with discharging wounds completely healed., yellow eyes typical of sickle cell persons have disappeared, the color urine has has turned from pale yellow to white - and a child who have developed ulcers in both arms and risked amputation of both limbs no longer has the ulcers and is a regular attendant in school.
- We initiated the development of a sickle cell registry for tracking sickle cell patients and their conditions. This will make possible a centralized repository for sickle cell information. It is still in its incubation stage as data acquisition and reporting protocols are being refined.
- Acquired an electronic health records system for keeping patient information. This is a web based system. The system in nonfunctional because of the absence of a high speed internet line in the clinic.

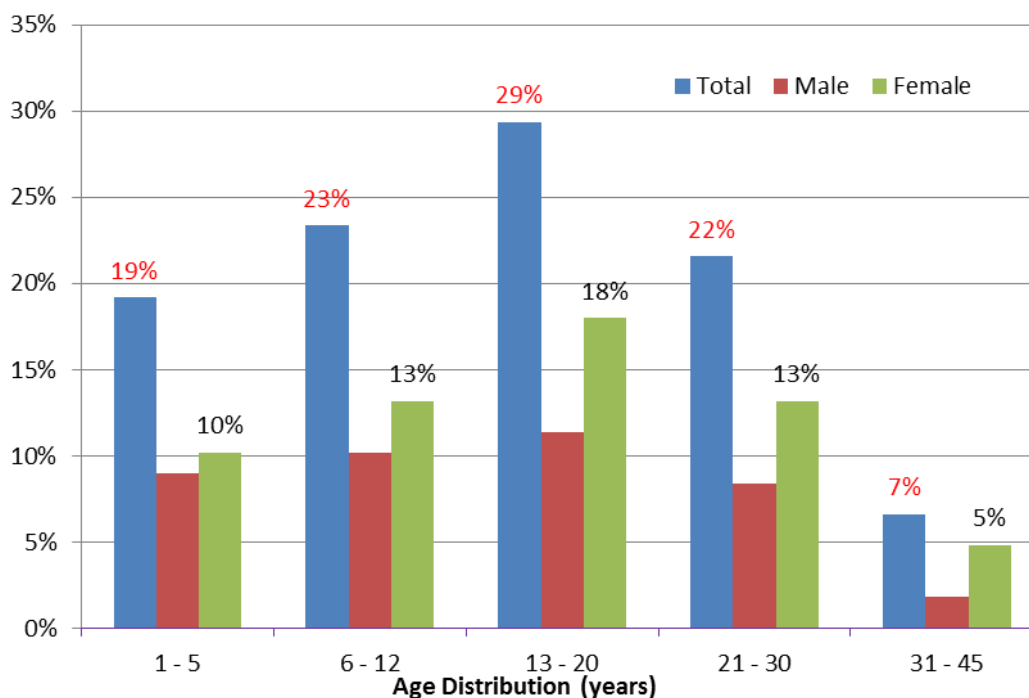


Challenges and Needs

- Comprehensive care team: medical doctor, nurses, laboratory technician, social worker, Information management technologist.
- Completion of the Sickle Cell Center - Phase II
- Hemoglobin Electrophoresis System and reagents
- Van for a mobile clinic and outreach activities
- Complete setup of a screening laboratory and necessary supplies
- Generator, water pump and heater,
- Construction Materials to include: sand, tiles, paint, tubes, electrical wires , switches and lamps,
- 5 medical exam tables and beds
- Blood pressure cuffs, syringes, scales and thermometers
- Office supplies, projector and sound system for presentations
- High speed internet access
- Funding to assist those who cannot afford and publication of educational materials.
- A graded/tarred access road to the center site under construction.

Age Distribution of Sickle Cell Cases

FJK Sickle Cell Cases: 2010 - 2012 (N=167)
source: FJK clinic data



Goals

- Provide accurate information on sickle cell disease and its management to healthcare providers, patients, schools, social service agencies and the general public.
- Provide national leadership in raising awareness and establishing standard protocols for patient services and research support initiatives.
- Offer regional workshops designed to advance the sickle cell cause.
- Mandate sickle cell testing and screening as clinical procedure for new born babies, expecting mothers and engaged couples.
- Establish a sickle cell registry for Cameroon and make sickle cell disease reportable into the centralized registry.
- Build an infrastructure to support programs and services
- Build and maintain a support network of collaborators and partners.

Partners and Collaborators

- Archdiocese of Bamenda, Cameroon
- Ministry of Public Health, Cameroon
- Total health Enhancement, Inc., California, USA
- Predestined Inc., Chicago, USA
- University of Illinois at Chicago, Sickle Cell Center, USA
- Mary Alphonse Bradley Fund, Servants of Mary, Wisconsin, USA

Prayer for Resources

Eternal and Merciful Father, hear our prayers for your children with sickle cell anemia. Unite their pains and sufferings with that of your Son on Calvary. Grant them the virtue of hope, that they may never lose their faith in thy loving purpose.

Lord Jesus Christ, through thy most Precious Blood, grant the Father John Kolkman Foundation the resources, and the wisdom to effectively use them, in assisting those with sickle cell anemia.

Holy Spirit, inspire in Sponsors and benefactors, the firm hope that, with your protection, the work begun will come to completion.

Most Holy Trinity, glorious is Thy Name at all times. Amen.

“Whatever you ask in prayer and faith, you will receive”— Mt 21:22

Ways You Can Help

1. Share this report and the sickle cell news with friends, family and coworkers. Make sickle cell a regular discussion topic.
2. Say the *Prayer for Resources* in this report, page 8, regularly as an individual, family or in your prayer or meeting group.
3. Make a financial or material donation towards any one of the needs on page
4. Organize a community event, special collections to support a need.
5. Adopt or sponsor a child in need. You submit a letter of interest and we match you and the family so they can acknowledge your support.
6. Share the sickle cell news; other ideas you have that can help advance the sickle cell cause.
7. Visit our website at <http://jkolkman.org> and send the link to a friend.

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This report is also available on the web at <http://jkolkman.org>