# Quality of life and follow up to 10 years in a cohort of 569 preterm infants born with a birth weight less than 1000 gr and/or less than 29 weeks of gestational age and *discharged from the Integral* Kangaroo Mother Care *(KMC) programs in Colombia.*

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# Background

- Prematurity and low birth weight are direct causes in great part of the neonatal mortality and morbidity (more than 30%). 1% of all live births and 10% of Low birth weight newborns have extremely low birth weight (less than 1000 gr) and/or extreme prematurity (less than 29 weeks).
- Although these statistics are low, this population group is the one with more sequels and who consumes more health resources of the preterm infants.
- The Colombian health system guarantees strict follow up of these babies up to one year of life; however, there is no structured program to continue monitoring these high-risk preterm infants.


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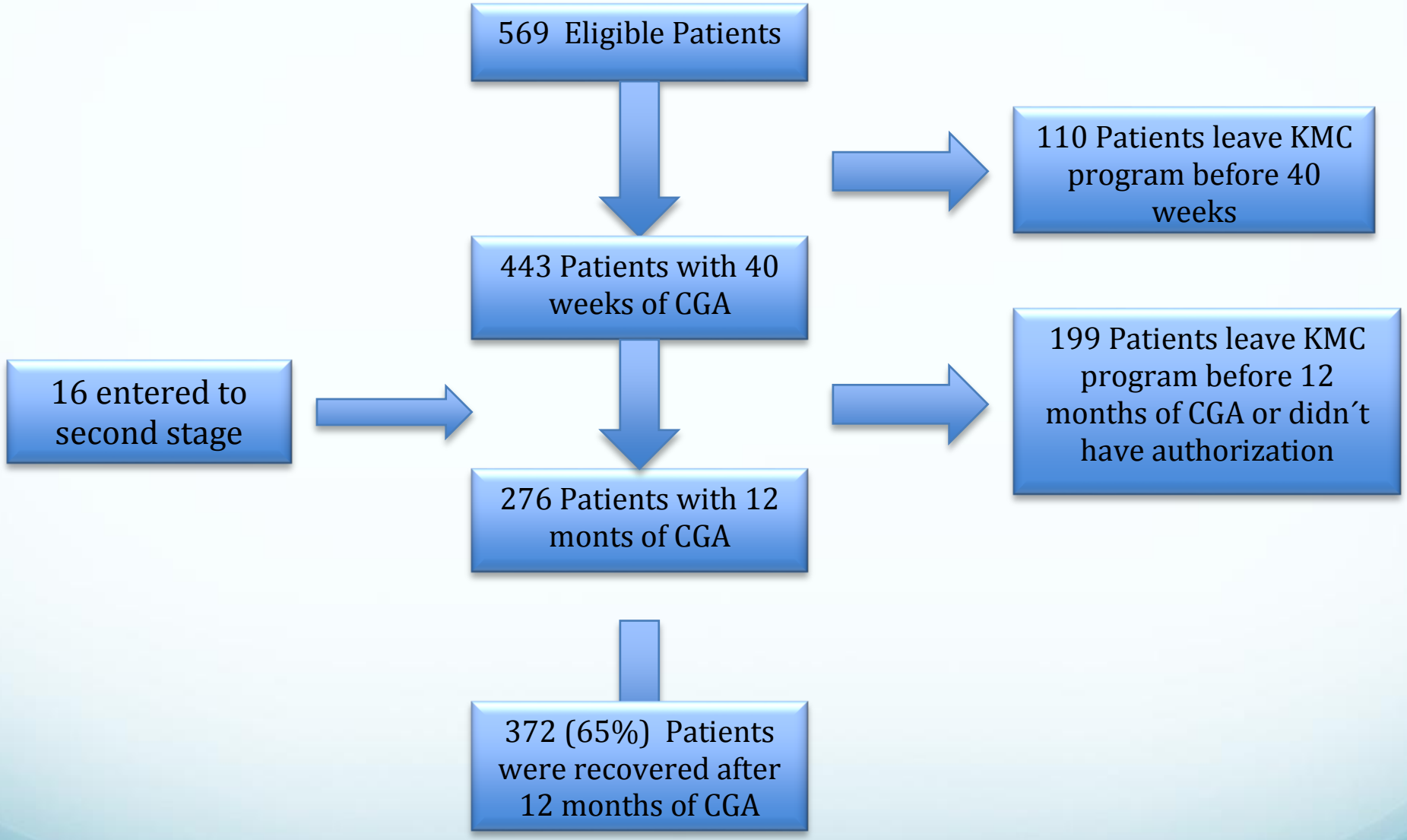
# Objective

- To explore the quality of follow up, clinic course and quality of life of preterm infants born with a birth weight less than 1000 gr and/or less than 29 weeks of gestational age after *discharged from three KMC programs.*

# Method

- Cohort of 569 infants less than 29 weeks and/or less 1000g, followed in three outpatient KMC Programs at Bogotá and Medellin, Colombia, between 2001 and 2011. After discharge from KMC program, the parents were contacted and answered a telephonic survey.

**Dynamic Cohort:**



# Results

- *443 of the 569 eligible preterms (78%) had follow up to 40 weeks of corrected gestational age and 276 (49%) up to twelve months. The reason is because their health insurance authorized KMC program only up to this time and they continued the follow. Perinatal records and*
- *Gynecobstetric background and monitoring was similar between recovered and no recovered patients.*
- *6%(34/569) of the initial cohort died.* 64,6% of this mortality occured during the first 6 months of life.

# Results

- *The median age of the patients in the moment of the telephonic survey was 4 years (10 months-11 years).*
- *Status of health was considered as pathologic  by their doctor in 26% of the patients between 13 and 24m, 37% 25-36m; 50% 37-48m; 47% 48-72m and in 46% of the more than 6 years old patients.*
- *63% (204/326) of the recovered patients had been hospitalized, 56% more than twice. 12.6% had been hospitalized in ICU.*

# Results

- *30% of the patients had chronic pulmonary diseases, 5.2% cerebral palsy or mental retardation and 2.7% seizures.*
- *The follow up was done by pediatrician in 72% of the patients, in 23% by general practitioner and in 3.6% by a nurse.*
- *The mean age for sustaining head was 6 months (±3.7m), for seating alone 8.8m (±2.8m), for crawling 11.5m (±3.7m) and for walking 16.6m (±5.7m).*
- *65% needed physical therapy, 39% language therapy and 7% had a history of loss of school years since 4 years old.*
- *55 % of the children with more than 6 years old at the moment of the survey were not practicing any sport .*

| Gross Motor | n | PC50 CA |
|---|---|---|
| **Sustaining Head** | 199 | 6m (2,0-36,0) |
| **Seating** | 236 | 8 m (5,0-24,0) |
| **Crawling** | 229 | 11 m (6,0-36,0) |
| **Walking** | 284 | 15 m (9,0-70) |

| Fine Motor | % |
|---|---|
| Had not started writing (>4y) | 9% |
| Difficulty in Writing (>5y) | 4% |
| Difficulty in Dressing (>6 y) | 81% |

| Disease | Pulmonary Chronic Disease | Readmissions |
|---|---|---|
| Recovered Cohort % | 30,0% (100/336) | 61% (206/336) |

**Neurological Outcomes:**

| Disease | IV Bleeding | Cerebral Palsy or MR | Seizures | Need glasses | Abnormal Audiometry |
|---|---|---|---|---|---|
| Recovered Cohort % | 32% | 5,2% | 2,7% | 27% | 7% |

# Conclusions

*The extremely low birth weight preterm infants have high rate of mortality and morbidity, specially respiratory and neurologic sequels that can impact not only their quality of life but also that of their family and the society. Its important to continue strict multidisciplinary follow up more than 12 months in order to guarantee the best possible development, growth and reduce their disease burden.*