Bringing them together
An essential role in retinoblastoma team; a disease coordinator

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Step back and Meta-science
Clinical Research

• Developing world
• No resources
• Treatment first
Early motivation, The spark

• "You can't manage what you can't measure" P Drucker

• And what is measured improves
How can we start

• Research is just asking question
Plans are nothing,
Planning is everything
Paving the road

- Handbook of Clinical Research Department
- Putting the policies
CCHE 57357 Vision

• The Children's Cancer Hospital Egypt 57357 will be an internationally recognized centre of excellence, magnet of care, and a model of a financially viable philanthropic organization.
CCHE 57357 Mission

• The mission of the Children's Cancer Hospital Egypt 57357 is to achieve cure and to **improve the quality of life** for all children with cancer regardless of race, creed or ability to pay. We will achieve this by:

• 1. Caring for children with cancer and their families with compassion, innovation and passion.

• 2. Serving as an international magnet of care by **providing effective clinical and management systems in treatment, education and research.** CCHE will share the knowledge gained with other healthcare centres nationally and internationally.
CCHE 57357 Mission

• 3. Being committed to research that will seek to understand the epidemiology of paediatric cancer, and improve prevention, early diagnosis and treatment effectiveness for the ultimate objective of cure without long term physical and psychological adverse effects.

• 4. Recognizing that achieving the goal of providing superior services depends upon a dedicated and highly trained staff; we place the highest priority on supporting personal and professional growth, and fostering a team environment. We regard our staff as the essence of our humanitarian effort.

• 5. Utilizing information & communication technology as an integral component of our patient care, research, and outreach programs.
CCHE 57357 Mission

• 6. Ensuring that the Administration and Board of Directors of the Children's Cancer Hospital Egypt and the Children's Cancer Hospital Foundation Board of Governors work in alliance to develop a **financially responsible strategy** for the sustainability of the hospital and fostering accountability to the hospital stakeholders and our generous donors, ensuring the best use of their contributions.

• 7. Recognizing our roots stem from the National Cancer Institute. We will continue a strong alliance and affiliation with the National Cancer Institute by **sharing services, clinical expertise, research, knowledge** and a vision of quality cancer care for all patients.

• 8. Serving our community by being a good employer, leading in **public health education and environmental issues** and caring for our neighbourhood.
57357 Hospital

• Leading change 2007

• Knowledge into action 2010
• “We can not teach any one but we can only facilitate”

Carl Rogers
Evidence – Based Medicine

• Integration of Latest available evidence with physician’s experience and patient’s preferences.
Success indicators

• New Co-operations: COG ARET 321
• Faster information retrieval: Building Our own Rb clinical research System
• Decision time improvement
Building our knowledge

Background

Foreground

• 1245 Paper
• Organized in 39 folders
Standardizing data collection

- Not used but replaced with eCCRb
Publications discussion

• 37 paper discussions in 2009 – 2010
  – Pediatric oncology
  – Pathology
  – Ophthalmology
  – Radiotherapy
  – Epidemiology
Bringing them together

• International efforts
  – Visits (ingoing -outgoing)
  – Publications
  – Societies
  – Conferences

• National Efforts
  – Publications
  – Conferences

• Internal shared interface
Societies - International

- **AACR** - American Association of Cancer Research
- **AAO** - American Academy of Ophthalmology
- **ARVO** - Association for Research in Vision and Ophthalmology
- **EACR** - European Association of Cancer Research
- **ACRP** - Association of Clinical Research Professionals
- **AACE** - Association for the Advancement of Computing in Education
- **ATA** - American Telemedicine Association
Societies - National

- EMS - Egyptian Medical Syndicate
- AFEBM - Arab Federation of *Evidence Based Medicine*
- EOS - Egyptian Ophthalmological Society
International connections
Telemedicine and Telepathology

• 25/8/2010  First Slide scanning
• Disease coordinator is responsible for sharing cases with external centers for discussions
Software Engineering

• Hospital Electronic Medical Records System
  – Forms, Standard

• Research System
  – Analysis, Design, Development, Implementation and Evaluation
  – Data Collection
Research and Follow-up system

- eCCRb
- CCHE Rb Research DB
Realtime statistics

Kaplan Meier Survival Curve for MB

- MBGTR
- MBSTR

Cumulative Survival Probability

Survival Duration in months
Patient Education

• Educational materials
• Consent Forms
Fundraising, financials and Biomedical engineering

- Tele-pathology
- TTT
- Protocol Budgeting
20 January 2011

- Research Institute of Ophthalmology 5\textsuperscript{th} Annual meeting. Cairo, Egypt.
- The first presentation of our 3 years results. 300 pages
Epidemiology of Retinoblastoma in Egypt.  
Samira Ezzat

Chemo-Response in Retinoblastoma.  
Alaa Haddad

Advanced techniques of radiotherapy in Retinoblastoma.  
Eman ElDebawy

Results of Retinoblastoma treatment in Children Cancer Hospital.  
Yasser Medhat

Efficiency of local therapies as early treatment and during follow-up.  
Adel Alei Eldin

Phthisis bulbi in Retinoblastoma, Children Cancer Hospital experience.  
Hala Taha
“Things do not change, we change.”

Henry David Thoreau
This smile has many behind
Success

• It means only seamless improvement
Lessons to learn

• We can build a research facility on limited resources
• Define your vision and mission
• Define the rules that manage connections with other disciplines
• Ask a question
• Study what others do
• Setting a preliminary protocol
• Studying its results
• Reaching a standard treatment protocol
• Share with others
2010 thanks
2010 thanks

A Language for Retinoblastoma: Guidelines and Standard Operating Procedures

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J. Reynolds and S. Olitsky (eds.), Pediatric Retina,
Today

• Complete infrastructure for clinical research
• 2 standard Treatment Protocols for Intra- and extra-ocular retinoblastoma
• Data management facility
• Junior staff
Future - team

• Joining more trials, establishing our own
• Further process improvement
• Further studying for the nature of the disease (cellular and molecular)
Conclusion

• Integrating a dedicated retinoblastoma clinical research coordinator has changed the team practice from expert domination and opinion-based decision making into evidence-based practice and research orientation.

• The new role was a successful cornerstone for developing the first clinical research team in the country.
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