

Progress Report August 15, 2011

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1- National Kidney Registry for Lebanon

The national kidney registry (NKR) was officially launched in March 2011. Up to date, 51 dialysis units (total = 58 units) have been enrolled and trained on the use of the NKR's web-based electronic database. Data for 1060 patients have been entered. This is a great start for the 5-months old registry, in a period when all hospitals are in the middle of accreditation activities.

Starting in early 2012, the national kidney registry will be officially used to file the monthly Ministry of Public Health forms and financial statements online. Be sure to enter all 2011 data for your patients into the registry before end of 2011.

سوف يتم تقديم المعلومات والفواتير المطلوبة شهريا من وزارة الصحة اللبنانية من خلال السجل الوطني لامراض الكلى عبر الانترنت ابتداء من اواخر عام 2012. تأكدوا من ادخال معلومات 2011 لمرضاكم بالكامل قبل نهاية العام.

Important features will be added to the NKR between mid August and end of September 2011:

1. Patients transferring from one hospital to another can now transfer their file in the registry to the new hospital. The new hospital where the patient is dialyzing will then be able to read only the patient's data at the previous facility but not make any changes to it. Also, patients who dialyze at a different facility during the summer months can have their data entered at that facility during that period.
2. A module called "MOPH Parameters" will be introduced to monthly updates. It contains data to be reported to the MOPH which are currently not part of the registry. This will enable you to generate completed MOPH forms automatically and do the billing online.
3. Starting in September 2011, quality control reports will be generated monthly for each dialysis unit separately. The reports will include for each patient queries of missing or error entries.

If patient transfers to you from another hospital

1. Inform registry coordinator (03-345164 / 70-956591) ← ابلغوا منسق السجل الوطني لامراض الكلى
2. Obtain patient consent to transfer file احصلوا على موافقة المريض الخطية لنقل ملفه
3. Transfers patient record to your facility ينقل المنسق ملف المريض الى مركزكم بعد تأكيد المعلومات

2- Research projects

The concurrent research program was launched in late 2010. Eight studies are in various stages of progress (see table below), and all of them are multi-center. The kidney disease research program (KDRP) is planned to engage nephrologists throughout the country in research projects, as well as graduate students, interns, residents and fellows at the seven medical schools. The table below provides study titles, primary investigators, summary and status update:

Research Projects Ongoing or in Progress

Specialty	Principle Investigator (s)	Title	Summary
Vascular Access	Salim Kabalan Jamal Hoballah	Factors in Vascular Access Failure or Success	Evaluate vascular access insertion practices in Lebanon and the factors associated with incidence of failed access. Establish guidelines for access insertion practice. Status: Partially funded by the Lebanese Council for Scientific Research (LCSR). Study starting in September 2011, # centers=5.
Osteodystrophy	Saade Abboud Mirey Karavetian	Dietitian's Role in Controlling Osteodystrophy	Examine the effect of full-time dietitian on compliance and outcomes of osteodystrophy among HD patients compared to existing practices. Status: Study started in March 2011, application for supplemental funding submitted to LCSR. MS students in dietetics at LU and USJ are involved.
Pediatric RRT	Chebl Mourani	Pan-Arab Clinical and Demographic Profile of pediatric kidney disease patients at initiation of RRT	Collect demographics and clinical data at initiation for pediatric kidney patients age 21 or below who present for CRI, dialysis or transplant among physicians who are PAPNA members throughout the Arab World. Status: data forms completed study to be launched in November 2011.
Transplant	Antoine Barbari	Profile of failed transplant patients initiated on dialysis	Study demographic and clinical profile of patients initiated on HD following a failed or rejected kidney transplant. Compare their outcomes to other incident HD patients. Status: Proposal in preparation – nationwide study.
Adequacy	Dania Shelala	Using a Permanent Catheter Permanently	Study HD patients in whom a permanent catheter is used permanently. Assess the historical clinical events leading to that condition and their morbidity / mortality compared to patients who continue to use AV access. Status: Proposal completed, looking for funding – nationwide study.
CKD Pre-RRT	Samir Mallat	Clinical and Demographic Profile of CKD Patients at Initiation of Dialysis	Study demographic and clinical profile of patients initiated on HD in Lebanon to inform planning for future growth in services and prevention programs. Status: Preliminary analysis done and presented at NKF 2011 conference. Full analysis in early 2012.
CKD Pre-RRT	Hafez Elzein	Demographics, Comorbidity and Outcomes in Patients with $15 \leq \text{GFR} \leq 60$	Identify the pool of patients presenting with $15 \leq \text{GFR} \leq 60$ (stage 3 or 4 CKD) at major labs throughout Lebanon over a 3 month period and assess demographics and clinical profile. Follow a random sample for 5 years to study emerging comorbidity and clinical outcomes. Status: Proposal completed, looking for funding – Laboratory based nationwide study.
Osteodystrophy	Salim Kabalan	Vitamin D3 Deficiency in Hemodialysis (HD) Patient and a Matching Sample of the General Disease Population	Determine the prevalence of deficiency levels of 25(OH) D3 in Lebanon among HD patients compared to a sample of the general disease population matched for gender and age over a two-year follow up. Status: Proposal in preparation – nationwide study.

3- Publications and presentations

- Preliminary real-time data became available for incident patients from the recently launched national registry and was presented by Dr Hafez Elzein in April 2011 at the National kidney Foundation spring clinical meeting in Las Vegas - USA. The abstract and presentation entitled “Demographics and Clinical profile of patients Initiated on Hemodialysis in Lebanon” are posted on the registry website.

Personnel of the Research Program

Oversight:	Scientific Committee
Registry P.I.:	Salim Kabalan, MD
Managing Director:	Hafez Elzein, MD, MS
Statistical Analyst:	Ahmad Abdallah, MS
Research Coordinator:	Elie Elhaj, MS
Renal Dietitian:	Mirey Karavetian, MS
System Programming:	SoftKube, S.A.R.L.

- The LSNH and the scientific committee of the research program in Nephrology are planning a scientific seminar session for November 2011 to present the data generated so far by the registry and research projects. Further information will be disseminated on the registry website & LSNH emails.

4- Partnerships and Sponsorships

The widest benefit of the research program in Nephrology is accomplished through a broad base of existing and planned partnerships and sponsorships:

- The LSNH partnered with the MOPH and the Syndicate of Private Hospitals to launch the National Kidney Registry. This collaborative effort provides the regulatory and operational support for the NKR to be implemented at all hospitals providing dialysis services and to include all dialysis patients in Lebanon.
- A long-term collaboration with the Lebanese National Council for Scientific Research (LNCSR) is being pursued to support the overall program, individual studies and graduate students and medical trainees using the program setting and data for their theses.
- Strong ties are being built with the seven medical schools in Lebanon. The research program in Nephrology will be open for participation of graduate students (masters and PhD) and medical trainees (interns, residents and fellows) in its projects.
- A number of pharmaceutical companies have committed to supporting the program. Talks are in progress with few more to initiate their support. These companies will be highlighted as sponsors in the registry website and in the registry national report.
- A number of Foundations are being approached for potential support of the program (Al-Waleed Bin Talal Fdn., Isam Fares Fdn, Rotari Club ... etc.)

The first national report of the kidney registry is planned for release in May 2012

التقرير السنوي الاول للسجل الوطني لامراض الكلى سوف ينشر خلال شهر أيار 2012

The first scientific seminar of the Research Program will be in November 2011.

الاجتماع العلمي الاول لبرنامج أبحاث امراض الكلى سوف يعقد في تشرين الثاني 2011

Expect this progress report three times a year by email and posted in the website WWW.kidneyregistrylb.com : For information on the registry & research program