

## LSNH Presidents' Addresses

The efforts of three committees of the LSNH were important to propel the National Kidney Registry in Lebanon to where it is now:

- Dr. Nabil Bassil's committee (2008-9) was involved in the early planning, design and database testing.
- Dr. Anwar Hatoum's committee (2010-11) was involved in the critical phase of database finalization and registry launch in March 2011.
- Dr. Jose Khabout's committee (2012-13) is now involved in shaping the full potential of the registry and its possible expansion into peritoneal and pediatric.

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### **Nabil Bassil, MD**

LSNH President (2008-09)

Dear Colleagues,

The initiation of the Lebanese Kidney Registry was a challenge to develop while ensuring transparency of the work and complete respect for anonymity. The nephrology community eventually rallied behind the project once they were sure that this Registry is the sole property of the Lebanese Society of Nephrology & Hypertension.

So the Registry was launched aiming to shed the light on the state of Nephrology in Lebanon: beginning with Hemodialysis treatment and moving on to other branches of Nephrology. The ability to compare and benchmark against international results was also emphasized. This process will help us pinpoint the strengths and weaknesses of our practices and in turn make it possible for us to plan the accommodation of our future needs.

In the hope that this project will continue to prosper, I would like to thank all of those who contributed to its success, and continue to nurture and support it into the future. Sincerely,

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### **Anwar Hatoum, MD**

LSNH President (2010-11)

Welcome to a successful event where conception meets completion. The National Kidney Registry was a dream since the inception of LSNH. After a long time

dreaming, it became a reality thanks to thoughtful planning, hard work and determination. The mission of the Kidney Registry is to improve the management of patients facing kidney failure and help improve the quality of their life and possibly save their lives. In its full realization, the registry and its associated comprehensive research program will cover all areas of Nephrology: dialysis, transplant and chronic kidney disease; in both adults and children. Finally, I would like to extend my heartfelt thanks to everyone who contributed and made the Kidney Registry a living success.

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**Jose E. Khabouth, MD**

LSNH President (2012-13)

The importance of having a database to understand what was happening in medical practice was highlighted as early as 1947 in the Framingham Heart Study which broadly shed the light on the development of vascular diseases.

This evoked the importance of Epidemiology as an integral part of medical learning and practice. This also planted the seeds for what we rely heavily on nowadays in the form of Evidence Based Medicine. Gradually, a framework was created to collect, store, analyze, interpret and report data. The concept of a registry database evolved, to capture parameters of interest to all active participants involved in the provision of services in a given medical field.

In all medical areas, especially in the management of chronic diseases, the presence of a registry is a must to evolve towards a best practice environment. This is true also in Nephrology.

The National Kidney Registry in Lebanon was launched in March 2011 to capture information on different aspects of our specialty with initial focus on adult hemodialysis. Although I fully agree on its creation and development, I still believe that a stronger involvement by public and private partners under the scientific umbrella of the Lebanese Society of Nephrology and Hypertension; have to be implicated in the realization of the fully developed registry.

A great effort has been made and we are thankful to private initiatives collaborating with our Society. More extensive brainstorming has to be made before expanding the National Kidney Registry into other areas of Nephrology practice.

## Guide to this annual Report

This report was prepared to follow the format of the web-based registry database. The registry consists of nine data modules divided into two segments: Fixed patient data (2 modules) and monthly updates (seven modules).

### *Registry Data: Pages 3-52*

The opening section (chapters 1-2) consists of introduction and methods. Then, section 1 consists of the fixed data modules (chapters 3-5) and section 2 consists of monthly update modules (chapters 6-11). Each of the database modules was presented in a chapter except the dialysis parameters and adequacy modules which were combined into one chapter.

### *Appendices: Pages 54-86*

The appendices contain: 1) the reference tables where detailed data are presented for all patients, by Incident/prevalent, and by region (Mohafaza), 2) list of performance measures for continuous quality improvement, and 3) description of the research program and the two studies currently in progress.

Tables were numbered by chapter number on the left of decimal, and sequence number on the right of decimal, starting with reference tables for that chapter followed by tables in the chapter body. Figures were numbered similar to tables, but appear only in chapters.

This report presents national data for HD patients in Lebanon during first year of the kidney registry operation. There were over 62% complete data records and more than 80% of parameters had reliable data. The registry is in evolution. Efforts will be relentless by the research team working with dialysis units' staff to improve performance, and upgrade the database content, clarity and practicality.

We apologize for any inaccuracies or deficiency in reporting, much of it was not possible to correct, so it was noted internally for quality improvement. We greatly appreciate your feedback, comments and suggestions for making the registry better. Write to us using this link:

<http://www.kidneyregistrylb.com/pages/home/contact/>

## Registry Database

The NKR uses a web-based electronic database for capture of data at the dialysis unit. The database is structured such that each unit has its own totally confidential space. At each unit, the designated coordinator(s) and/or professional staff login using their own account username and password. No one else is able to access that space, not even the registry research team.

The database captures data at the patient level and consists of two main sections:

1. The first section contains patient's fixed data: a demographics module and a module for the dialysis initiation session. The first dialysis session module captures primary cause, vaccinations, vascular access insertion, pre-dialysis nephrologist encounter, lab data, and medications, existing comorbidities and a segment for patients who started dialysis after suffering a failed kidney transplant.
2. The second section contains patient's monthly updates. The visit date for each month is the date of the last dialysis session in that month. All measurements, events and utilizations that occur in that month are entered. This section consists of 7 modules: dialysis parameters, anemia, mineral balance, vital signs and anthropometrics, dialysis adequacy, medications and outcomes and complications.

The database is backed up daily for 7 days, then weekly for the previous three months, and then monthly for the prior 24 months. A built-in download utility enables a dump of the database from any of the back-ups. Database dumps are stripped from patient contact and identifying information and generated as one file for each of the nine modules.

Each dialysis unit, patient and patient's monthly visit has a unique identifier that is sequentially assigned. Each patient monthly visit date anchors one record, and all unique visit numbers of a given patient contain the patient's unique numerical identifier. Two mapping files are also generated. One file links the unique patient numerical identifier to the unit's unique numerical identifier. The second file contains the link between patient's numerical identifiers and his/her personal identifiers and contact information.

Data files can be accessed only by the registry operational director and the statistician, using two-level password protection. The stripped export files are the ones used for quality assurance and analytic activities. Mapping files containing patient names are accessed only in the occasion of a patient transferring from one facility to another. Personal information is verified prior to transfer to the new facility to maintain continuity of patient record in the registry. The new facility staff can access the past patient's history at the previous facility on a read-only basis.

Each patient signs a main consent form prior to their inclusion in the registry, and a "transfer of record" consent form when they transfer to a new facility. In practice, some technical issues or information deficiencies may be uncovered in the database. Comments and suggestions are continuously fielded and documented so they can be incorporated into the next version update, expected to be produced every 2-3 years.

## Preface

The national kidney registry (NKR) and research program was proposed by an expert team at Partners in Wellness and Research (PWR) to the Lebanese Society of Nephrology and Hypertension (LSNH) in July 2009. The LSNH is a specialized professional organization representing the practice of renal medicine, dialysis, transplant and hypertension, and is integrated into the Order of Physicians in Lebanon. PWR is an independent research group with expertise in clinical, outcomes and epidemiological research and large database design, maintenance, quality assurance and mining.

The mutual desire was to impact significant change in the provision of clinical care to patients with chronic kidney disease (CKD) in Lebanon. The program targeted initially patients on hemodialysis (HD), to be followed by peritoneal dialysis, pediatric CKD and kidney transplant over a five-year span.

The launch of the Lebanese NKR in March 2011 was an important milestone that impacted and promoted the provision of excellent care to all HD patients in Lebanon. Practices such as measurement of patient's height and vital signs, calculation of body mass index, percent body fat and body water and capture of important clinical outcomes such as mortality, hospital and emergency room admissions, vascular access and other emergent complications were introduced and standardized.

In retrospect, the years in the run-up to the establishment of the NKR were important to the registry creation. A pilot project at 18 dialysis centers in Lebanon was conducted from May 2007 to October 2008, and collected data from 1164 HD patients. Data collection forms in MS-Excel were used to extract information from patient charts and also through direct interview of patients after taking their informed consent. The project was directed by Drs. Sana Ghaddar and Hafez Elzein and implemented through the volunteer work of over 25 students from the Nutrition Department at the American University of Beirut. Special thanks for their role and contribution to the success of that pioneer experience.

The pilot project resulted in summary data for all Lebanon, and facility-specific summary reports on demographics, vascular access, dialysis adequacy, anemia, osteodystrophy and mineral balance, comorbidity and medications. The results were presented in February 2009 at a special conference of the LSNH and at the National Kidney Foundation's Spring Meetings in the United States in 2009 and 2010. Facility-specific reports were presented at all 18 facilities over 8 months up to May 2009.

After the pilot project, the goal of creating a Lebanese kidney registry gained momentum. The LSNH and PWR signed an agreement in October 2009 to initiate developmental work for the registry. A number of pharmaceutical companies provided the basic funding for the NKR development. A scientific committee was formed in November 2009 consisting of representative of the LSNH, MOPH, PWR and the 7 medical schools in Lebanon. The committee was actively involved in the design and oversight of the registry.

Two years after its launch, the registry enlists 64 of the 66 dialysis units and over 2800 of the 3200 active HD patients in Lebanon. Its maturation continues to progress in content, patient coverage and analytic detail. Full maturity of a registry usually takes 5-7 years of progressive quality improvement. The adoption of the renal community and support of the MOPH has set the registry on that successful path.

A zeal for innovation has underpinned the NKR success. The MOPH provided regulatory backing, with logistic and scientific support by the LSNH and the Syndicate of Private Hospitals. Exceptional teamwork succeeded in fulfilling our remit towards the issuance of this inaugural report.

Salim Kaban, MD  
**Principle Investigator**

Hafez Elzein, MD, MS  
**Operational Director**