# Rapport Activités du Collège – 2018 – Part 2

***Résultats d'une étude avec les centres de traitement de l'insuffisance rénale chronique et les Registres néphrologiques belges (GNFB et NBVN)***
***concernant le placement de patients en dialyse sur la liste d'attente pour une greffe de rein – 2018.1; et***
***concernant la faisabilité d'une visite d'inspection du centre de dialyse – 2018.2***

## 1. Study project 2018.1: what are the obstacles to put dialysis patients, aged between 18 and 64 years of age, on the transplant waiting list ?

### 1.1 Introduction

A kidney transplant is considered the best form of non-curative renal replacement therapy in terms of both efficiency and quality of life, and at a less expensive cost than a continued treatment with dialysis.

The importance of "kidney transplantation" is recognized in the recently ratified agreement about "dialysis financing"; the number of transplants of the last 3 years is included in the formula for calculating the percentage of "low care / low cost" renal therapies.

The NBVN as well as the GNFB registry have repeatedly shown that on average only 33% of dialysis patients between the ages of 18 and 65 are actively waiting on the Eurotransplant [ET] kidney transplant waiting list [Table 1]. Intuitively, a much higher percentage would be expected.

Table 1: Prevalence of the active ET kidney (Ki) transplant waiting list and dialysis patients covered in the NBVN and GNFB registries – all ages and age category 18-64 years.

| **Belgium** | *All ages* active total Ki WL Belgium | *All ages active Ki-only WL* Belgium | *All ages active Ki+Pa WL* Belgium | 18-64 yrs active Ki-only WL Belgium | 18-64 yrs dialysis patients Belgium | 18-64 yrs dialysis patients NBVN | 18-64 yrs dialysis patients GNFB | 18-64 years % dialysis patients active on the WL |
|---|---|---|---|---|---|---|---|---|
| 31/12/2011 | 883 | ***837*** | *19* | **740** | **2204** | 1277 | 927 | **33.5% (Belgium)** |
| 31/12/2012 | 791 | ***748*** | *26* | **648** | | | NA | |
| 31/12/2013 | 770 | ***721*** | *31* | **632** | | | NA | |
| 31/12/2014 | 878 | ***821*** | *40* | **691** | | **1045** | NA | **36% (NBVN)** |
| 31/12/2015 | 871 | ***813*** | *37* | **687** | | **1001** | NA | **32% (NBVN)** |
| 31/12/2016 | 797 | ***742*** | *30* | **640** | | | NA | |
| 31/12/2017 | 849 | ***793*** | *25* | **677** | | **1061** | NA | **31% (NBVN)** |
| 31/12/2018 | 824 | NA | NA | NA | | NA | NA | |

## 1.2 Aim

1. Survey of the reasons, prohibiting dialysis patients from being listed on the kidney transplant waiting list – age category – 18-64 years of age – reference date – January 1, 2018 [NBVN].

2. Survey of the time flow, starting from the proposal "transplant option" to the final active waiting status on the ET waiting list, considering all 'intermediate stations' (start investigations, registration transplant center, additional interventions, registration at Eurotransplant, … ) [GNFB].

## 1.3 Results

### 1.3.1 – Causes of non-listing on the ET waiting list - NBVN

*A. Background:*

On January 1, 2018, 1205 patients – aged 18-64 years – were treated with dialysis, either hemodialysis or peritoneal dialysis, in the NBVN organization. This population corresponds to only 26% of the total dialysis population [N=4700].

| NBVN<br>Age:<br>18-64 years | ET-Waiting list<br>Transplantable<br>**"callable"** | ET-Waiting list<br>Not-transplantable<br>**"not callable"** | Not on the ET<br>Waiting list | Total | Centers |
|---|---|---|---|---|---|
| **1/1/2015** | 378 – 36% | 201 – 19% | 466 – 45% | 1045 | 25/26 |
| **1/1/2016** | 323 – 32% | 147 – 15% | 531 – 53% | 1001 | 23/26 |
| **1/1/2018** | 331 – 31% | 90 – 8% | 640 – 60% | 1061 | 25/26 |

The number of actively waiting dialysis patients remains constant over the recent years. The large difference between the categories "Not-transplantable" and "Not on the ET Waiting list" is due to a misconception of the word "not transplantable", mixing its clinical and administrative meaning.

*B. Characteristics of the dialysis population 18-64 years*

The age group 55-64 years is the largest [N=544; 57%] of the dialysis population 18-64 years and has the highest percentage dialysis patients not listed on the transplant waiting list [N=369; 68%].

| **Age group** | **Transplantable**<br>"callable" | **Not-transplantable**<br>"not callable" | **Not on the waiting list** | **Total dialysis patients** | |
|---|---|---|---|---|---|
| 18-24 | 10 | 3 | 8 – 38% | 21 | *2%* |
| 25-34 | 35 | 7 | 30 – 42% | 72 | *7%* |
| 35-44 | 62 | 15 | 61 – 44% | 138 | *13%* |
| 45-54 | 92 | 22 | 172 – 60% | 286 | *27%* |
| 55-64 | 132 | 43 | 369 – 68% | 544 | *57%* |
| **Total** | **331** | **90** | **640 – 60%** | **1061** | *100%* |

There is no difference regarding gender.

The distribution of the underlying kidney disease varies considerably per age category, and the age group mainly explains the percentage "Not on the waiting list". Patients with cystic kidneys (ADPKD), immunological kidney diseases and diabetic nephropathy in the context of type 1 diabetes mellitus are often younger and have the lowest percentage "not on the waiting list". Patients with diabetic nephropathy in the context of type 2 diabetes mellitus are older and have, as such, a clearly higher percentage "Not on the waiting list".

| **Renal disease** | **Transplantable** "callable" | **Not-transplantable** "not callable" | **Not on the waiting list** | **Total dialysis patients** | |
|---|---|---|---|---|---|
| Immunological glomerulonephritis | 94 | 17 | 119 – 52% | 230 | *22%* |
| Tubulo-interstitial nephritis | 39 | 7 | 93 – 67% | 139 | *13%* |
| Type 2 diabetes | 23 | 13 | 102 – **74%** | 138 | *13%* |
| Vascular disease | 31 | 12 | 75 – 64% | 118 | *11%* |
| Unknown | 31 | 11 | 72 – 63% | 114 | *11%* |
| Cystic kidneys | 46 | 13 | 33 – **36%** | 92 | *9%* |
| Other renal disease | 23 | 5 | 48 – 63% | 76 | *7%* |
| Type 1 diabetes | 24 | 5 | 41 – 59% | 70 | *7%* |
| Hereditary renal disease | 17 | 3 | 31 – 60% | 51 | *5%* |
| Irreversible acute kidney failure | 2 | 3 | 18 – 78% | 23 | *2%* |
| Cardiorenal syndrome | 1 | 1 | 8 – 80% | 10 | *1%* |
| **Total** | **331** | **90** | **640 – 60%** | **1061** | *100%* |

No analysis was done regarding the time the patients were already on dialysis.

It should be noted that potential candidates for a kidney transplant are hardly on the ET transplant waiting list before starting dialysis.

Because the allocation factor "waiting time" is calculated from the start of the (last) dialysis period in the ET kidney allocation program [change made in 1999] and the allocation factor "waiting time" substantially impacts the position on the final allocation list in the event of a suitable kidney donor, pre-emptive placement on the waiting list or accelerated placement after the start of dialysis is less mandatory to speed up a selection because the waiting time is either absent or very low.

*C. Reasons – Not on the waiting list*

The College survey (completed by 23 of the 26 dialysis centers) showed some corrections about transplantability with regard to the earlier NBVN survey. Lesser patients were on the renal transplant waiting than initially reported.

The total patients not being on the waiting list amounted to 632 patients – no information was given on 17 patients. The current analysis population consisted of 615 patients.

One quarter of the dialysis patients is either currently involved in an assessment of the candidacy for a renal transplantation (20% - N=136) or awaiting the final registration at the Eurotransplant waiting list (5% - N=31). Not surprisingly this is particularly the case among the

patients aged less than 45 years and/or having either a renal cystic disease or immunological renal disease.

| **Reasons of non-listing on the transplant waiting list (N, %)** | | |
|---|---|---|
| | | |
| No ongoing transplant evaluation | 448 | 73% |
| | | |
| **Ongoing transplant evaluation** | **88** | **14%** |
| **Transplant evaluation finished – awaiting evaluation by the transplant center** | **7** | **1%** |
| **Following visit transplant center, extra examinations ongoing / additional surgery planned** | **41** | **6%** |
| | | |
| Awaiting registration on the Eurotransplant waiting list | 31 | 5% |
| | | |
| Total | 615 | 100% |

A medical contra-indication is the main reason why patients are not involved in an evaluation for a transplantation [73%].

Besides truly somatic or mental issues, several centers stressed upon the "unchangeable" non-compliant behavior with regard to smoking, drinking of alcohol or use of illicit drugs.

Some patients have been evaluated by the dialysis centers but were declined as a suitable transplant candidacy following evaluation by a transplant center. The current analysis does not provide information on the acceptance and refusal rate by the transplant centers, upon referral for evaluation.

Fifteen percent of the patients declared not to be interested to be transplanted, regardless of their age.

| **No ongoing transplant evaluation due to (N, %) :** | | |
|---|---|---|
| | | |
| **Medical contra-indication : somatic and/or mental illness, persistent non-compliant behavior (smoking, use of alcohol, use of illicit drugs, … )** | **307** | **69%** |
| **Decline by the transplant center after visit** | **19** | **4%** |
| | | |
| No interest of the patient, though potential candidate | 69 | 15% |
| | | |
| **Immigrant – no legal residence permit** | **37** | **8%** |
| Other<br>- potential recovery of renal function<br>- just transferred from another dialysis center<br>- on waiting list outside Belgium | 16 | 4% |
| | | |
| Total | 448 | 100% |

Several dialysis patients could not be evaluated due to their immigrant status, and their corresponding lack of an official health insurance. As long as these patients don't have a residence permit, the Belgian transplant centers are obliged to refrain them from any transplant evaluation. As such, many (young) patients are condemned to a long (and more expensive) dialysis period, due to the lengthy procedure of the Immigration Office.
On the other hand, as long as the return to their land of origin is pending, it might not be wise to transplant the patients in the meantime, since anti-rejection medication might not be available in their land of origin, provided they have to go back; the fate of their renal transplant might be comprised upon return.

For some patients, an evaluation of transplant candidacy is not appropriate since there is a reasonable chance of recovery of their renal function with potential freedom from dialytic treatment.

*D. Conclusion*

The option "survival benefit through kidney transplantation" can only be offered selectively to the dialysis population, theoretically suited to the age criterion of 18-64 years.

Medical contraindications and non-compliance behavior are the main reasons for not preparing patients for a kidney transplant.

Fortunately, the quarter of the dialysis patients not on the waiting list is indeed in an active evaluation process or just finished it. This constant flow in the assessment of dialysis patients as potential transplant candidates demonstrates a positive attitude towards renal transplantation among the dialysis centers.

All Belgian kidney transplant centers have a guideline for examining a (pre-)dialysis patient for the purpose of a successful kidney transplant. In addition, clear information how to select suitable dialysis patients aiming at such a successful kidney transplantation is available in the European Renal Best Practice, under the auspices of the ERA-EDTA organization[1].

A more structured questionnaire why the "kidney transplant" option was excluded might serve as an additional quality indicator of the care performance of a dialysis center. However, the NBVN organization doubts the added value of such an interrogation.

Any dialysis patient being listed on the kidney transplant waiting list requires constant evaluation of his/her persistent suitability by the local nephrologists and by the transplant center to ensure a successful renal transplantation on behalf of the recipient. Various kidney transplant centers have opted for a "return day" in order to "check" this recipient suitability, but also to refresh what to do upon the call that a donor kidney is available, the transplant procedure and the follow-up after transplant.

Finally, according to this study, the NBVN nephrologists are well aware to the option of transplantation, and there is no major indication that suitable dialysis patients are unnecessarily refrained from this option.

[1] Abramowicz D, Cochat P, Claas FH, Heemann U, Pascual J, Dudley C, Harden P, Hourmant M, Maggiore U, Salvadori M, Spasovski G, Squifflet JP, Steiger J, Torres A, Viklicky O, Zeier M, Vanholder R, Van Biesen W, Nagler E. European Renal Best Practice Guideline on kidney donor and recipient evaluation and perioperative care. Nephrol Dial Transplant. 2015 Nov;30(11):1790-7.

1.3.2 – Trajectory from patient selection till listing on the active waiting list - GNFB

The results will be made available by the GNFB in June 2019.

## 2. Study project 2018.2 : Analysis of the feasibility of an inspection visit of the dialysis centers - NBVN

The aim is to investigate to what extent the visitation of a dialysis center might contribute to the improvement of the quality of dialysis care, in addition to the existing initiatives of the Flemish, Brussels and Walloon governments, and to the Federal instructions. Implications in terms of organization, financing and reporting must be investigated in advance prior to its implementation.

2.1 Evaluation by the GNFB: this communication will follow in May 2019

2.2 Evaluation by the NBVN:

*A. Initiative created by the NBVN*

In 2018, a center review report was elaborated at the level of the individual dialysis center, in which 5 quality indicators were evaluated. The selection of these quality indicators was based on the experience of the Nefrovisie organization that groups the Dutch dialysis centers : epidemiology of the dialysis patients, survival of the dialysis patients, dialysis access of the hemodialysis patients, listing on the transplant waiting list and renal function upon start of chronic dialysis [or indication for chronic dialysis]. There is a major variation of these quality indicators among the NBVN dialysis centers.

This center review report will be offered to the NBVN dialysis centers in May 2019.
However, a procedure how to deal with and to evaluate so-called positive and negative out-layers has not yet been designed by the NBVN Board of Directors.

*B. Initiatives of the Flemish government* – department Welfare, Public Health & Family – Healthcare inspection.

The Healthcare Inspectorate of the Flemish government is already carrying out various visitations. The philosophy of these inspections focusses on 2 processes:

- ✓ system supervision - focused on structure, process and quality systems - this is currently been handed over to accreditation organizations - see below.
- ✓ compliance monitoring - focused on the concrete assessment of care processes (surgical, internal - cardiology, mother & child, etc.). Such visits are not announced on beforehand.

It should be noted that a specialized care monitoring process looking at the dialysis patient is currently under development. Hopefully the NBVN organization will be consulted when drawing up the requirement framework.

*C. Overview of the hospital accreditation of the NBVN dialysis centers*

All 26 NBVN dialysis centers (high-care dialysis) reside in a hospital, having an active accreditation, issued either by JCI or by NIAZ-Qmentum.

| **JCI – Joint Commission International** | **NIAZ – Qmentum** |
|---|---|
| | |
| Aalst, OLV ziekenhuis | Bonheiden, Imeldaziekenhuis |
| Antwerpen, AZ Monica | Brugge, AZ Sint-Lucas |
| Antwerpen, GZA Sint-Augustinus | Gent, AZ Sint-Lucas |
| Antwerpen, UZ Antwerpen | Gent, UZ Gent |
| Antwerpen, ZNA<br>*( has also a separate ISO-9001 certificate for the dialysis department and outpatient clinic )* | Hasselt, Jessaziekenhuis |
| Brugge, AZ Sint-Jan | Lier, H.-Hartziekenhuis |
| Brussel, UZ Brussel | Malle, AZ Sint-Jozef |
| Dendermonde, AZ Sint-Blasius | Sint-Niklaas, AZ Nikolaas |
| Genk, Ziekenhuis Oost-Limburg | Turnhout, AZ Turnhout |
| Gent, AZ Maria Middelares | |
| Ieper, Jan Yperman Ziekenhuis | |
| Kortrijk, AZ Groeninge | |
| Leuven, UZ Gasthuisberg | |
| Roeselare, AZ Delta | |
| Ronse, AZ Glorieux | |
| Sint-Truiden, Sint-Trudo Ziekenhuis | |
| | |
| **N= 2909 dialysis patients – 64%** | **N= 1612 dialysis patients – 36%** |

There is no information available about the Kliniek Sint-Jan / Clinique Saint-Jean, in the Brussels-Capital Region.

*D. Advice*

The Netherlands has a lot of experience with the procedure of visitation of a dialysis center made by an ad hoc peer-review committee, consisting of nephrologists and dialysis nurses, and checking the basic prerequisites of renal care – drafted by the dialysis community (www.nefrovisie.nl/visitatie-certificering), in addition to a concomitant certification by an external certification body - such as NIAZ-Qmentum or HKZ.

Because of the emergence of a more hospital-wide accreditation in The Netherlands, one questions about the content and necessity of this dialysis-specific accreditation, due to the large overlap between the two accreditation programs.

In Belgium, the direction of inspection would be reversed. Is there a need for a more specific visitation of a dialysis center, apart from the broader hospital inspection ? The Flemish initiative to implement such a specific inspection is currently prepared at the department of Welfare, Public Health & Family.

We recommend that the dialysis centers, with its nephrologists and renal nurses, are consulted in time. The NBVN organization is currently not involved in this project.

So, the implementation of inspection visits – designed and governed by the College of Nephrologists – might be superfluous till further notice.

Namens het college,
Au nom du collège

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