FIRST BELGIAN REGISTRY IN ATOPIC DERMATITIS

START-UP OF THE TREAT REGISTRY IN UZ GENT

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INTRODUCTION

- Atopic dermatitis (AD) is a common, chronic, itchy, inflammatory skin disease that can have a major impact on the quality of life of patients and their family.
- Since June 2020 dupilumab, the first biologic for the treatment of severe AD, is available in Belgium next to phototherapy and classic systemic immunosuppressants. Other biologics and JAK inhibitors are expected to join the therapeutic armamentarium soon.
- This new generation of therapeutics in AD have been studied in clinical trials, however, real world data is lacking.
- Collecting clinical data in a prospective registry could help to obtain information for clinical practice, for answering research questions and for reducing costs. The results are useful to implement in guidelines and decision aids.
- In order to start up a registry, we decided to join the TREAT NL registry (TREatment of ATopic eczema, the Netherlands), part of the international TREAT initiative. This is a national registry in which information is collected prospectively about children and adults diagnosed with AD who are starting on photo- or systemic immuno-modulatory therapy.
- Patient characteristics, physician reported outcomes and patient reported outcomes are collected at time of initiation of therapy and 1, 3, 6 , 9 and 12 months after initiation of therapy. The patient is followed up three monthly for the next 4 years.

OBJECTIVE

- to describe the start-up of a prospective registry of AD patients who start a systemic treatment or phototherapy.
- to present baseline characteristics of the patients that were included in the registry in 2021.

METHODOLOGtY

STEP 1: The electronic patient file was adapted to incorporate the TREAT core outcome set. Approval of the medical ethics comittee was obtained.
STEP 2: The clinical flow in our patient consultation was reorganised to maximise inclusion in the registry and to ascertain follow up consultations.
STEP 3: After giving consent, eligible patients were included in the registry and data from each visit was processed in a database.
STEP 4: A first analysis of the baseline characteristics of the first 17 included patients was performed

RESULTS

Table 1: Baseline characteristics of the first 17 patients included in TREAT registry UZ Gent

Demographics	
Total included	17
Sex	
• Male	8
• Female	9
Age average	32,76 years
BMI average	25,4

Treatment	
UVB	1
Ciclosporin	1
Dupilumab	10
Upadacitinib	4
Baricitinib	1

Outcome	Average (min – max)
EASI	14, 88 (3,6 – 41,6)
SCORAD	52,81 (39,44 – 82,80)
NRS itch 7 days	7,18 (4-10)
VAS sleep loss	4,63 (0 – 8,2)
DLQI	11,59 (4-19)
POEM	19,41 (13-28)

DISCUSSION & CONCLUSIONS

- The start-up of a registry by joining TREAT nl proved to be feasible
- The implementation of the registry encourages to systematically gather and analyse clinical parameters and PRO's, thereby improving clinical care.
- The results of this first analysis need to be interpreted with care because:
  - Sample size is currently limited to 17
  - Patients on dupilumab are over represented because inclusion in the registry was easier to combine with the clinical visits
  - Clinical parameters (such as EASI, SCORAD) at inclusion in the registry (i.e. initiation of therapy) may differ from values at the time of submission of reimbursement documents because of rescue therapy (e.g. intensive course with topical steroids).